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*I find ecstasy in living; the mere sense of living is joy enough.*

*Emily Dickinson*





University of Alberta

Treatment Decisions at Birth: The Perspectives of People with Disabilities

by

Julia M. Ichikawa



A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Education

Department of Educational Psychology

Edmonton, Alberta

Fall 2001





**University of Alberta**

**Faculty of Graduate Studies and Research**

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **Treatment Decisions at Birth: The Perspectives of People with Disabilities** submitted by **Julia M. Ichikawa** in partial fulfillment of the requirements for the degree of **Master of Education**.





## DEDICATION

*To my father and mother, Ben & Shoko Ichikawa, with love and gratitude*







## **ABSTRACT**

The purpose of this study was to examine the perspectives of people with disabilities concerning decisions regarding the medical treatment of newborns with disabilities. The design for this study was qualitative in nature, consisting of in-depth, open-ended interviews with seven adults who were born with disabilities.

The thesis begins with a historical overview of attitudes toward newborns with disabilities and their treatment. Profiles of each participant are presented to provide the background and context for understanding the participants' perspectives concerning treatment decisions. The responses of the participants are organized into three overarching categories: making treatment decisions in newborns' best interests, procedural aspects of making treatment decisions, and criterion factors in making treatment decisions. The participants' perspectives reveal that the issue of treatment decisions is not only difficult and complex, but also multifaceted. In short, the diversity and complexity that characterize the perspectives of the participants are comparable to the broad spectrum of views reflected in the literature.



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## **CHAPTER ONE**

### **INTRODUCTION**

#### **Background of the Research**

A review of the literature indicates that infanticide, the deliberate killing of babies, has been practiced throughout history (Amundsen, 1987; Bouillon-Jensen, 1995; Moseley, 1986; Rosenblum & Budde, 1982; Weir, 1984). Although historically both healthy babies and those with disabilities were killed for several reasons, with varying responses from both society and the law, the practice of infanticide has had especially significant implications for babies born with disabilities. Likewise, compared with earlier historical periods, advances in neonatology have not only added new dimensions to the issue of infanticide, but have also raised unprecedented ethical challenges concerning the value of babies with life-threatening conditions. The development of sophisticated medical technology, surgical procedures, and pharmaceuticals in neonatal intensive care have made it possible to save the lives of many newborns who previously would not have survived (Anspach, 1993; Guillemin & Holmstrom, 1986; Lantos & Moseley, 1995). At the same time, however, many of these babies who survive with medical treatment have significant disabilities for their entire lives (Anspach, 1993; Batshaw, 1997). Consequently, it has become necessary to make decisions whether to withhold or withdraw medical treatment from babies born with significant disabilities (Anspach, 1993; Batshaw, 1997; Lantos & Moseley, 1995; Magnet & Kluge, 1985; Weir, 1995).





Such decisions—whether to initiate or continue medical treatments—are complex, especially as babies cannot express preferences or participate in the decision-making process. These decisions must be made by others. Traditionally, babies lived or died as a result of decisions made privately by parents and physicians. However, their survival is now also affected by decisions made by others, such as ethicists, administrators, legal practitioners and judges, legislators, and policymakers (Anspach, 1993; Dellinger & Kuszler, 1995; James, 1989; Lantos & Moseley, 1995; Weir 1984). While these decisions regarding medical treatment are meant to be made in the baby's best interests, a perusal of the literature reveals that a diversity of perspectives exists among those who are involved in the decision-making process (Anspach, 1993; Batshaw, 1997; Dellinger & Kuszler, 1995; Guillemin & Holmstrom, 1986; Horan & Delahoyde, 1982; James, 1989; Weir, 1995). These studies also indicate that decisions regarding the medical treatment of newborns with disabilities have become the subject of much debate and controversy.

However, in the midst of this ethical dilemma, in which numerous perspectives vie for influence and authority, one significant aspect seems to be absent—that is, the voice of people with disabilities, that is, the voice of individuals who have lived the experience of disability. As stated by Dr. John A. Robertson, then of the University of Wisconsin Law School, “one must decide for whose benefit is the decision to withhold treatment from a child with severe birth defects. Is no life better than one of low quality? The person to ask is an individual who has a disabling birth defect” (Koop, 1989, p. 105). As a result, this research study examines the



perspectives of people with disabilities concerning decisions regarding the medical treatment of newborns with disabilities.

### **Need for the Research**

The literature reveals that virtually no research directly addresses the views of people with disabilities concerning decisions regarding the medical treatment of newborns with disabilities. Although there are studies that focus on the perceptions of people with disabilities concerning euthanasia and assisted suicide of adults, the issue of newborns needs to be examined independently. It cannot be assumed that the views held by people with disabilities regarding euthanasia or assisted suicide can be generalized to decisions to withhold or withdraw medical treatment from babies born with disabilities.

At the same time, questions may be raised concerning the necessity of an additional perspective when numerous viewpoints already abound. However, unlike the various perspectives expressed by those currently involved in the decision-making process, people with disabilities are able to address this issue from the perspective of knowing the meaning of disability from first-hand knowledge and experience. This is significant, as the projected future of babies requiring medical treatment is characterized by considerable uncertainty regarding both the degree and range of disability.

Similarly, the literature indicates that those involved in the decision-making process are heavily influenced by personal perceptions and presumptions of living with a disability. Previous studies, specifically related to health care professionals, have found that a majority of pediatric practitioners report no non-professional





contact with individuals with developmental disabilities (Wolraich, 1980).

Furthermore, research has revealed that not only do physicians severely underestimate the long-term life satisfaction and well-being of people with disabilities (Bach & Tilton, 1994; Gerhart, Koziol-McLain, Lowenstein, & Whiteneck, 1994; Saigal, 2000), but they also significantly underestimate critically-ill newborns' actual chances of survival (Clyman, Sniderman, Ballard, & Roth, 1979; Lee, Penner, & Cox, 1991). Consequently, attitudes that devalue the lives of people with disabilities can affect approaches to treatment. Health care professionals who believe that a life with disability is not tenable may think they are considering the best interests of newborns with disabilities by advocating decisions to withhold or withdraw medical treatment. Yet, these treatment decisions are based on suppositions held by people without disabilities. Therefore, exploration of this issue from the perspective of people with disabilities provides invaluable insights concerning decisions regarding the medical treatment of newborns with disabilities.

### **Significance of the Research**

Research which elicits insights concerning decisions to withhold or withdraw medical treatment from babies with disabilities from the perspective of people with disabilities will contribute to furthering understanding of this issue and continuing development of this discussion. Equally important, it will raise awareness and stimulate thinking and, in doing so, it will set an agenda for further research in this area.





This study entails interviews with seven adults who were all born with physical disabilities of varying degrees. Their views concerning the medical treatment of newborns with disabilities bring a new and much needed perspective to this ethically-charged issue.





## CHAPTER TWO

### LITERATURE REVIEW

This chapter will provide a historical overview of attitudes toward newborns with disabilities and their treatment. Although infanticide of healthy babies and those with disabilities alike is still widely practiced in many parts of the world, the focus of the literature review will be restricted to infanticide of infants with disabilities in western civilizations.

#### Greco-Roman Civilization

In Greco-Roman civilization, infanticide was practiced not only for population control, but also for eugenic reasons. An infant's worth was measured by his or her potential contribution to society, reflecting belief in the doctrine of the survival of the fittest. Beauty and physical perfection were favored in Greco-Roman culture. Thus, although unwanted healthy infants were also killed, whether an infant lived or died was determined by the absence of any observable abnormalities. Both unwanted healthy infants and those born with defects were commonly left to die by exposure (Bouillon-Jensen, 1995; Moseley, 1986; Weir, 1984).

It is believed that infanticide was practiced to the greatest degree in Greco-Roman society in Sparta, where military strength was highly valued (Amundsen, 1987; Bouillon-Jensen, 1995; Moseley, 1986). Only infants who were considered likely to become proficient soldiers were allowed to survive. The Spartan custom is depicted in the following account:

But if it was ill born and deformed they sent it to . . . a chasm-like place at the foot of Mount Taygetus, in the conviction that the life of that which nature



had not well-equipped at the very beginning for health and strength, was of no advantage, either to itself or to the state” (Plutarch, *Life of Lycurgas*, 16).

Additional literature also provides evidence of the extent to which infanticide was practiced, particularly of infants with abnormalities. In the *Republic*, Plato condoned the practice of infanticide, stating that society was better served if newborns with defects were “hidden away, in some appropriate manner that must be kept secret” (Plato, *Republic*, 460). Similarly, Aristotle viewed infants with birth defects as less than human and recommended that “there be a law that no deformed child shall live” (Aristotle, *Politics*, 1335b).

Superstitious beliefs also contributed to the acceptance of infanticide as a reasonable method of eliminating newborns with defects (Amundsen, 1987; Bouillon-Jensen, 1995). Birth defects, or *portentosi*, meaning “unnatural” or “monstrous” births, were seen as ominous signs and it was believed that only by killing the baby would any misfortune be circumvented.

Greek law did not prohibit the killing of infants with birth defects, nor did it provide protection for healthy infants who were considered to be of little social value, such as females (Amundsen, 1987; Bouillon-Jensen, 1995). Moreover, early Roman law had little jurisdiction in domestic affairs. The Roman tradition of *patria potestas* granted fathers absolute domination over the family, including the power of life and death over children (Bouillon-Jensen, 1995; Moseley, 1986; Weir, 1984). Consequently, the practice of infanticide was considered part of a Roman father’s right, as head of the household.





## **Judeo-Christian Traditions**

In contrast to the Greeks and Romans, Jews and early Christians condemned the killing of unwanted human life (Bouillon-Jensen, 1995; Ferngren, 1987; Moseley, 1986). Jews believed that human life had intrinsic value, to be regarded as sacred from the moment of birth, because humans were created in the image of God. Thus, Jews condemned the killing of infants, equating infanticide with murder. Similarly, early Christians adopted the Jewish doctrine that humans were divinely created; they also adhered to the principle of the sanctity of all human life. As such, the rescue and nurture of infants who had been exposed was viewed as a Christian duty.

However, it was not until the time of Constantine, when Christianity became more widespread and was officially recognized, that Christians' opposition influenced greater society, and led to infanticide being regarded as a crime (Bouillon-Jensen, 1995; Moseley, 1986). In 318 A. D., Constantine issued the first secular law directed against the killing of infants. This was followed by legislation enacted in 374 A. D., by Valentinian, who declared the practice of infanticide a homicide that was punishable by law. While the laws did not explicitly differentiate between healthy infants and those with birth defects, the writings of early Christians indicate that the denouncement of infanticide extended to all infants (Bouillon-Jensen, 1995; Ferngren, 1987).

## **The Middle Ages**

Although Christianity continued to spread throughout Europe, the Middle Ages gave rise to a mixture of Christian beliefs, pagan myths, superstition, and



folklore. This intermingling of beliefs had significant implications for the practice of infanticide, particularly concerning infants with birth defects.

The changeling myth was commonly believed to explain the birth of an infant with abnormalities; newborns with defects were thought to be “changelings” (Bouillon-Jensen, 1995; Moseley, 1986). The myth claimed that fairies, motivated by envy of the beauty of human babies and a desire to acquire a soul, replaced the “real” baby with an elfin child. A similar Christian version of the myth attributed the birth of an infant with birth defects to demonic intervention by which the devil had stolen the “real” baby, leaving a demon-child in its place. Consequently, regardless of whether the pagan or Christian rendition of the myth was believed, newborns with abnormalities were frequent victims of severe physical abuse often resulting in death. It was believed that only extreme measures, such as beating or burning the baby, would compel the fairies to rescue their elfin child or exorcise the devil from the baby.

During the Middle Ages, the belief that witches were responsible for both the birth and death of infants with defects was also widespread (Ferngren, 1987; Moseley, 1986). Both mothers who gave birth to newborns with abnormalities and midwives who delivered the infants were suspected of being witches. Likewise, the death of infants with birth defects was viewed as a result of being suffocated by a witch and placed in bed to appear as though the parent had overlain the infant.

In fact, overlying was the most frequent cause of infanticide during the Middle Ages (Bouillon-Jensen, 1995; Ferngren, 1987; Moseley, 1986). Overlying became so common a method of infanticide that laws specified that mothers were not



to sleep in the same bed with their babies (Moseley, 1986). However, because intent was nearly impossible to determine in cases of overlying, prosecution was extremely difficult. In most cases, the courts were not able to establish whether the death of an overlain infant was unintentional or deliberate (Ferngren, 1987).

Moreover, although there was legislation against the practice of infanticide, application of the laws was restricted to acts of direct killing, excluding deaths as a result of “accidental” means. Furthermore, it did not generally warrant the type of conviction that the murder of an adult would incur (Weir, 1984). Infanticide was primarily regulated by church courts rather than secular courts throughout most of the Middle Ages. Therefore, although the Church had the authority to impose penalties for infanticide, married mothers and unwed mothers were treated differently (Bouillon-Jensen, 1995; Moseley, 1986; Weir, 1984). The punishment for married mothers convicted of killing an infant was relatively light, involving public penance, but minimal compared to the murder of an adult. On the other hand, unwed mothers who committed infanticide were ostracized and punished severely; they were often put to death by drowning, impalement, live burial or other means. In the later Middle Ages, secular legislation regarding infanticide was enacted. Infanticide was then considered to be a serious crime equivalent to that of homicide. However, rarely did prosecution occur; in practice, infanticide was generally overlooked.

### **Renaissance and Reformation**

By the fifteenth century, foundling homes were established, in response to the widespread practice of infanticide directed against both healthy, but unwanted infants and those with birth defects (Bouillon-Jensen, 1995; Moseley, 1986; Weir, 1984).





Although foundling homes continued to provide an alternative to the practice of infanticide throughout the sixteenth and seventeenth century, in reality, these institutions were often equivalent to condemning infants to death through neglect and disease as a result of overcrowded conditions. Moreover, the majority of infants with abnormalities were transferred to the care of a wet nurse who would take the infant to the countryside and “inadvertently” kill the baby while feeding him or her. This practice of employing wet nurses was seen as a convenient method of circumventing the law and the teachings of the Church against infanticide.

### **Eighteenth and Nineteenth Century**

During the eighteenth and nineteenth century in Europe, acts of infanticide continued to be prevalent and attempts to legally curtail its practice were unsuccessful (Bouillon-Jensen, 1995; Weir, 1984). Although infanticide was considered homicide, it was not perceived to be the equivalent of killing an adult; juries showed greater leniency toward those accused of killing their infants. The bodies of dead infants were commonly found in rivers and other public places such as parks, provoking public outcry and protest against the practice of infanticide. Physicians were particularly prominent in leading reform movements, effecting mandatory documentation of all births and deaths, as well as the licensing of foundling homes (Bouillon-Jensen, 1995; Moseley, 1986; Weir, 1984). Despite these efforts, the practice of infanticide continued throughout Europe.

While the history of infanticide in North America is not as well documented as compared to that in western Europe, it is believed that English practices influenced attitudes toward infanticide in the colonies and that the practices paralleled those of



the British experience (Weir, 1984). It should be noted, however, that while present Canadian laws concerning infanticide are founded upon statutes originally enacted in England (Bauman, 1997), the United States lacks any legislative initiatives against this practice (Oberman, 1996).

### **Early Twentieth Century**

Between the years 1939 and 1945, infanticide was actively practiced in Nazi Germany, under the bureau of the Committee for the Scientific Treatment of Severe, Genetically Determined Illness. Although innumerable “undesirables” were put to death during this time, children with disabilities were the first to suffer medicalized killing following the signing of a secret order by Hitler, which permitted infanticide on the basis of disability. Children with disabilities were separated from their families and admitted to medical clinics where they were euthanized. Likewise, health care professionals and midwives were required to notify authorities when an infant was born with birth defects. Failure to comply resulted in punishment and liability. Furthermore, there appears to have been considerable public endorsement for the infanticide of newborns with birth defects, including substantial support from parents and relatives of children with disabilities (Bouillon-Jensen, 1995; Smith, 1997, 2000).

### **Present Day**

Historically, medical interest in newborns was limited as there was little that medicine could do to enhance the survival of critically-ill newborns. Today, significant advances in medicine, such as the establishment of neonatal intensive care units (NICUs), have made it possible to save the lives of many newborns who



previously would not have survived. The NICU is a highly technical and sophisticated environment that is staffed by an interdisciplinary team comprised of highly skilled health care professionals who are dedicated to the treatment and survival of critically-ill newborns (Thurman, 1993).

The origins of neonatal intensive care are found in the late 1800s with the work of two Europeans, Tarnier and Budin. These physicians observed that premature infants who were able to maintain a constant body temperature had an increased chance of survival; this discovery led to the development of the incubator. Subsequently, special care nurseries for premature infants were founded in the United States by Hess, inspiring the conception of neonatal intensive care units. The phenomenal success of these units in the treatment of critically-ill newborns led to the establishment of NICUs across North America in the 1970s, primarily at major university medical centers. By 1976, there were more than 125 NICUs; there are now reported to be more than 700 units (Horbar & Lucey, 1995). In addition, neonatology, a discipline which had not existed prior to 1960, emerged as the fastest growing subspecialty within pediatrics by the 1980s. Specifically in Canada, the first NICUs were established in the 1960s (Magnet & Kluge, 1985).

There are three different classifications of NICUs, offering a graduated level of care. Level I NICUs perform risk assessments and are capable of resuscitating and stabilizing newborns. While these facilities provide care for newborns without complications, Level I units primarily provide convalescent care for babies who have returned from Level II or Level III centers. Level II NICUs, in addition to offering the services of Level I units, are equipped to provide intermediate care for moderately





ill newborns. The Level III units are the most advanced and comprehensive of the three facilities, and they are equipped to treat the most critically-ill newborns with severe complications.

It is primarily within the context of the NICU that treatment decisions are made. Extraordinary advances in neonatology have added new dimensions to the issue of infanticide, raising unprecedented ethical challenges concerning the value and medical treatment of babies with life-threatening conditions.

Health care professionals who provide care to critically-ill newborns in NICUs are presented with a variety of medical conditions and complications. Canadian statistics reveal that in 1995, 13,629 congenital anomalies or birth defects were recorded, with a rate of 483.5 for every 10,000 births (Health Canada, 1997). The most common anomalies were musculoskeletal (130.6 per 10,000 births) and heart defects (78.8 per 10,000). The most frequent musculoskeletal defects were congenital dislocation of the hip and clubfoot, each of which was more common than anomalies of the digestive system, circulatory system, central nervous system, urinary system, genital organs, cleft lip/palate, and Down syndrome. Congenital anomalies are a leading cause of neonatal deaths, accounting for 33% of neonatal (within 28 days of age) deaths and 23% of postneonatal (between 28 days of age and a baby's first birthday) deaths overall (Statistics Canada, 1997). However, the extent to which these deaths are the result of the withholding or withdrawal of medical treatment is unknown. Nevertheless, research has revealed that the withholding and withdrawal of medical treatment has been and is currently being practiced in NICUs.



In the 1970s and 1980s, considerable debate focused on whether newborns with Down syndrome or spina bifida should receive medical treatment for complications associated with their disabilities. Studies revealed that in the United States, the withholding of standard medical treatment from infants with Down syndrome was supported by two thirds of pediatricians; more than half of infants referred with spina bifida were denied medical treatment (Gross, Cox, Tatyrek, Pollay, & Barnes, 1983; Shaw, Randolph, & Manard, 1977; Todres, Krane, Howell, & Shannon, 1977). Similarly, it was found that 54% of babies with Down syndrome at the Hospital for Sick Children in Toronto were denied medical treatment (Girvan & Stevens, 1974). Since 1985, it has become more difficult to find cases in which babies have been withheld medical treatment based on the diagnosis of Down syndrome or spina bifida. However, lay accounts report that there are still numerous health care professionals who express negative attitudes toward children with Down syndrome (Rutler & Seyman, 1999).

While attention has now shifted to cases of extremely premature and low birth weight newborns, who usually have multiple complications, research indicates that the majority of deaths occur as a result of withholding or withdrawal of medical treatment. Ryan, Byrne, Khun, and Tyebkhan (1993), who examined the medical treatment of infants in Canadian neonatal and pediatric intensive care units (PICUs), found that 69% of deaths in the NICUs and 34% in the PICUs were the result of withdrawal of medical treatment. The researchers also noted that certain cases involved the termination of treatment based on the high likelihood of long-term disability. Similarly, a more recent study by Wall and Partridge (1997), who



reviewed the medical records of all infants who died during a three-year period at the NICU at the University of California, San Francisco, revealed that, overall, 73% of deaths were attributable to the withholding or withdrawal of medical treatment. In 23% of deaths, quality of life was the only documented reason health care professionals reported for withholding or withdrawal of medical treatment.

Specifically in the Netherlands, where euthanasia has been practiced without legal consequence since 1973 (Smith 1997, 2000), the Royal Dutch Medical Association (KNMG) has been publishing a series of reports concerning life-terminating actions with incompetent patients. The first of the series ("Report of the Royal Dutch Society of Medicine," 1991), initially released in 1988 and followed by the publication of a more definitive report in 1990, defends the termination of medical treatment of newborns with severe disabilities on the basis of an "unliveable life" prognosis. Within this report, the definition of termination of medical treatment includes both the withholding of medical treatment and the active killing of a baby in circumstances in which the withdrawal of medical treatment does not result in immediate death (Jochemsen, 1992). A study (van der Heide et al., 1997) which examined the deaths of 338 infants between August and November 1995, found that 57% of deaths were the result of withholding or withdrawal of medical treatment. Of the 57%, 18% of deaths were preceded by treatment decisions based on the infants' poor prognosis, and 8% of infants were administered drugs with the explicit intention of hastening death.

Issues concerning the medical treatment of newborns with disabilities were made public in 1973, when a research study conducted by Duff and Campbell was





published in the *New England Journal of Medicine*. Duff, a professor of pediatrics, and his associate, Campbell, found that 43 of 299 (14%) deaths in the intensive care nursery at the Yale-New Haven Hospital had occurred following a decision to withhold treatment based on newborns' extremely poor prognosis for meaningful life. Although the publication of this and similar articles incited both public and professional debate in the United States, regulations pertaining to the medical treatment of newborns with disabilities were nonexistent for almost a decade.

It was not until the 1980s, when several neonatal cases involving controversial treatment decisions were made public, that efforts were made to regulate the treatment of newborns with disabilities. The term "Baby Doe" originated in 1982 (Caplan, 1992; Horan & Balch, 1985; McMillan, Engelhardt, & Spicker, 1987), in a dispute over a newborn with Down syndrome and tracheo-esophageal fistula, a gastrointestinal malformation in which there is an incomplete separation between the trachea and esophagus. This condition, if not surgically repaired, results in death as the abnormal connection between the trachea and esophagus causes food or drink to go into the baby's lungs. In this particular case, Baby Doe died six days after birth following the parents' decision, based on the advice of their obstetrician, not to consent to corrective surgery. This decision was made primarily on the premise that a baby with Down syndrome could not attain a "minimally acceptable quality of life." Although an attempt was made by a pediatrician to force treatment, the courts ruled that the parents had the right to refuse medical treatment for their baby. This case was similar to numerous others that had occurred during the preceding decade, most



notably involving the selective non-treatment of newborns with Down syndrome and spina bifida.

As a result of the Baby Doe case, the United States Department of Health and Human Services outlined regulations stipulating the withholding of medical treatment on the basis of disability as discrimination. Threatened by the loss of federal funds, health care facilities were required to post signs announcing the regulations, in addition to providing a toll-free hotline to report instances of non-treatment.

Subsequently, the United States Congress passed amendments to the Child Abuse and Treatment Act of 1984—often referred to as the revised Baby Doe regulations—that defined the “withholding of medically indicated treatment” as child abuse and neglect, rather than discrimination. The violation of the Baby Doe regulations carries fairly minor penalties. Neither criminal nor civil actions are authorized or threatened by the regulation. The maximum sanction is a loss of a limited amount of federal financial assistance (Batshaw, 1997; Dellinger & Kuszler, 1995). The Baby Doe regulations are perceived as ineffective governmental attempts to control a very complex area of medical treatment and decision making (Weir, 1995).



In short, western cultures share a long and checkered history of infanticide of babies with disabilities that continues up to the present day. This history of infanticide is characterized by three general trends as follows. First, the primary responsibility for making life and death decisions of infants with disabilities has transferred from parents to physicians and other health care professionals. Second, the contemporary framework within which infanticide takes place is based on



bioethical principles rather than religious beliefs. Thirdly, differential treatment of infanticide observed in the past by the judicial system continues to the present day.

This overview of the history of attitudes toward newborns with disabilities and their treatment provides the background for the current study. The following chapter will present the research method of this study.





## CHAPTER THREE

### RESEARCH METHOD

#### Approach to the Research

Decisions concerning the selection of a research design often lead to a consideration of research alternatives, particularly various quantitative and qualitative approaches. Although the relative contribution of quantitative and qualitative methods has been the focal point of a long-standing debate, examination of these two approaches reveal that they are characterized by differing strengths and weaknesses. Nevertheless, decisions pertaining to the selection of a research design are ultimately determined by the research question and the purpose of the research (Bogdan & Biklen, 1998; Denzin & Lincoln, 1998; Patton, 1990). Research which focuses on testing hypothetical-deductive generalizations is well suited to experimental or quantitative methods. In contrast, research which endeavors to understand human experience inductively and holistically within a specific context is more appropriately served by naturalistic or qualitative methods. Accordingly, a qualitative approach was selected for this study, as it purposed to examine and understand the perspectives of people with disabilities concerning treatment decisions of newborns with disabilities.

Equally important, while both qualitative and quantitative methods provide means to capture individuals' points of view, qualitative inquiry enables the researcher to investigate selected issues as perceived by individuals *in depth and in detail* (Bogdan & Biklen, 1998; Denzin & Lincoln, 1998; Patton, 1990). A



qualitative approach provides the means to gain a profound understanding of individuals' personal experiences, values, attitudes and beliefs through the dialogue of in-depth, open-ended interviews. This is in contrast to quantitative methods which may utilize standardized measures, such as questionnaires and surveys, by which the perspectives of individuals are determined from a limited set of preformulated response categories to which numerical scores are assigned. As such, quantitative measures may oversimplify intricacies inherent in examining individuals' points of view. Qualitative inquiry, on the other hand, takes into consideration dynamic complexities which cannot be measured quantitatively, allowing individuals to provide authentic, first-person accounts of their experiences, values, attitudes and beliefs, resulting in a more comprehensive and more complete understanding.

The specific research design of this study, although qualitative in nature, cannot be classified according to any of the familiar theoretical frameworks of qualitative research. The inclusion of an interview guide, and the lack of participant observation and theory generation, exclude this design from phenomenology, ethnography, and grounded theory, respectively. As such, the term "descriptive" or "sensitization" has been suggested as a framework for research which emphasizes an accurate and thorough presentation of a particular group's viewpoint (Knafl & Howard, 1984). Within this framework, qualitative findings are considered significant in and of themselves, since it is the richness and detail of the data which provide an understanding of the participants' perspectives.



## Participants

Participants for inclusion in this study were selected using purposeful sampling (Patton, 1990). As Patton explains, “the logic and power of purposeful sampling lies in selecting ‘information-rich cases’ for study in depth” (p. 169). Therefore, the researcher sought individuals with disabilities who could provide insights pertaining to treatment decisions concerning babies born with disabilities. Patton also delineates several strategies for purposefully selecting information-rich cases, of which three were incorporated in this study—maximum variation sampling, criterion sampling, and snowball or chain sampling.

Maximum variation sampling aims to discern common themes which emerge out of a diverse, heterogeneous sample, while at the same time recognizing the uniqueness of each individual’s experience. Thus, participants who collectively reflected a diversity of characteristics were selected with the expectation that both the individual perspectives and the emergent common themes would contribute toward a deeper understanding of treatment decisions concerning babies born with disabilities.

Although participant variation was desirable, criterion sampling was also applied in selecting individuals for the study. This was intended to assure the quality of the sample by predetermining criterion characteristics. Criteria for selection of the participants in the study included the following: individuals had to have been born with a disability; their disability had to have had a significant impact on their lives; they had to be willing to self-disclose, and they had to be 18 years of age or older.

The third strategy, snowball or chain sampling, was used for locating information-rich individuals. To begin with, a number of researchers affiliated with





the university were approached and informed about the study; a request was made for information-rich participants. These researchers then recommended well-situated individuals who identified potential participants. Each potential participant was subsequently contacted by telephone by the researcher who explained the nature of the research study, confirmed whether the participant met the criterion characteristics, obtained verbal consent to participate, and arranged an appointment for an interview.

Three men and seven women participated in the study. However, three interviews were excluded from the data analysis because, from further discussion, it became known that these individuals did not meet the criteria for selection as specified previously for the following reasons. Two of these individuals had initially stated they had been born with a disability; it was only when their disability was discussed in detail towards the end of the interview that they explained that their disability had not manifested itself until middle childhood. The third individual, while willing to talk about himself and his disability, was more reticent about discussing his perspective concerning the issue. As a result, the data analysis focused on the interviews of the remaining two men and five women.

The participants' disabilities included osteogenesis imperfecta (two participants), muscular dystrophy (one participant), spinal muscular atrophy (two participants), and cerebral palsy (two participants). The participants had all been identified as requiring medical treatment or intervention at birth or shortly thereafter. All participants used a power wheelchair for mobility. Although the participants had previously resided in group homes or with their immediate families, each of them currently lived in his/her own home with varied levels of assistance from personal



assistants. The participants ranged in age from 22 years to 54 years, with an average age of 40 years and seven months. Four participants were single; two were married to each other, and one participant was married to an individual without disabilities and had two children. The educational level ranged from completion of grade 10 to a Master's degree. One participant was a full-time mother; one was employed part-time; one was completing a college certificate with the possibility of pursuing a second undergraduate degree; and four were not employed. Two of these individuals had retired from their respective careers as a result of the progressive nature of their disabilities. However, both these participants were active volunteers, serving on various boards of directors and organizations related to disabilities.

### **Data Collection**

Data for the study were collected using in-depth, open-ended interviews. Interviewing allows the researcher to enter into and understand the perspective of the individual being interviewed (Kvale, 1996; Patton, 1990; Rubin & Rubin, 1995). "Qualitative interviewing begins with the assumption that the perspective of others is meaningful, knowable, and able to be made explicit" (Patton, 1990, p. 278).

In collecting qualitative data through open-ended interviews, various approaches to the design of the interview may be adopted. This study combined the interview guide approach with the standardized open-ended approach (Patton, 1990) to facilitate the interview process. A standardized interview guide comprised of a set of questions derived primarily from the research literature was developed in advance, with careful consideration given to the wording and sequencing of the questions. However, at the same time, the interview guide was not so tightly defined as to limit



the researcher from exercising the flexibility to probe and pursue pertinent aspects in greater depth. To ensure the relevance and clarity of the questions outlined in the interview guide, the researcher's supervisor and other university researchers were asked to review the questions prior to the initiation of the research. The interview guide (see Appendix A) was modified according to their suggestions for purposes of pertinence and comprehensibility.

Prior to beginning the interview, the researcher explained the purpose of the study and participants were asked to read and sign a written consent form (see Appendix B). The researcher took care to develop a rapport with the participants and to create an atmosphere which would encourage open responses. Each participant was interviewed individually, with the exception of the married couple who requested that they be interviewed together. The interviews were held in private, at a location of the respondent's preference—either at the participant's residence or at the university. All interviews were recorded using a portable tape recorder and an omnidirectional microphone. The interviews were later transcribed by the researcher and verified for accuracy by comparing the transcripts with the tape recordings. The interviews ranged from 45 minutes to two hours in duration.

### **Data Analysis**

To begin with, a profile of each participant was developed. These profiles were written with the intent of creating a context that would allow the reader, through the researcher, to know the participants vicariously. Therefore, the profiles not only serve to introduce the participants, but also help the reader to gain a deeper understanding of their perspectives concerning the issue of the study. As Denzin





(1998) stated, “An event or process can neither be interpreted nor understood until it has been well described” (p. 323). Thus, an effort was made to describe the participants’ disabilities, and to portray the participants’ lives in relation to their disability.

The primary source of data for the analysis was the interview transcripts. The data were analyzed for descriptions, patterns, themes, and relationships, drawing on methods of analysis put forward by various qualitative methodologists (Bogdan & Biklen, 1998; Denzin & Lincoln, 1998; Glaser & Strauss, 1967; Miles & Huberman, 1994; Patton, 1990).

The process of data analysis began with several rereadings of the transcribed interviews to increase familiarity with the data as well as to enhance understanding. The data were then coded by underlining segments of the participants’ responses and recording notes in the transcript margins, indicating preliminary categories. This process of coding the data was guided by the specific focus of particular questions included in the interview guide. Following the coding of the data, segments which appeared to form clusters were organized in terms of the preliminary categories. Finally, as the categories were clarified and refined, themes and sub-themes were identified from the data within each category. Throughout the analysis, the data was verified and cross-checked constantly to ensure accuracy and consistency.

### **Ethical Considerations**

Application for ethical clearance was made to the Ethics Review Committee of the Department of Educational Psychology to ensure that the program of research complied with the ethical standards set forth by the University of Alberta. Each



participant was asked to read and sign a written consent form prior to participating in the research. The consent form explained the purpose of the study, as well as the nature of the research, an interview which would be tape recorded and transcribed. Participants were informed that their involvement in the research was voluntary and that they could refuse to answer any questions or discontinue the interview at any time.

Confidentiality guidelines were explained. Participants were assured that the information shared in the interviews would be used only for research purposes. Participants were also made aware that their anonymity would be protected by the use of pseudonyms in the analysis, presentation, and publication of the research.



## CHAPTER FOUR

### RESEARCH PARTICIPANT PROFILES

This chapter introduces the participants of the current study by describing their disabilities as well as portraying the participants' lives in relation to their disability. Each profile is based on the information reported by the participants during the interviews. Specific medical aspects of the participants' disabilities have been supplemented by research presented in *Children with Disabilities* (Batshaw, 1997). For the purpose of confidentiality, the participants have been assigned pseudonyms.

#### Anne

Anne is 37 years old and has *osteogenesis imperfecta* (OI). OI is a genetic bone disorder associated with significant weakness of the bone. OI results from a mutation in one of the genes required to produce collagen, a protein compound that is a primary structural component of many parts of the body. Collagen, embedded with calcium crystals, makes up approximately two-thirds of bone and it is this protein-mineral mixture which gives strength to the bone. Impaired collagen synthesis results in abnormal or decreased cartilage formation, causing brittle bones that are susceptible to fracture. In fact, during the birth process, babies with OI risk sustaining multiple fractures or even dying of complications due to skull fracture. Anne described that at birth, she had fractures in both legs, as well as in one arm. Within two to three hours of birth, physicians had aligned and immobilized Anne's fractures by means of casting. Anne reported that she remained in the hospital for one month before her mother was permitted to take her home. At that time, Anne was placed in





a body cast and physicians instructed her mother not to lift her out of the crib for at least one year.

Because fractures can occur with little or no trauma, individuals with OI may have as many as 20 to 30 fractures of the bones in their limbs during childhood.

Although Anne did not specifically state the number of fractures she had sustained as a child, she commented, “Growing up, I had many, many, many, ma-a-any broken bones.” Because of the numerous fractures children with OI sustain, there is often the possibility that the disability may be confused with physical abuse. Anne recounted that her mother received numerous inquiries from social services suspecting abuse because of the frequency with which Anne was hospitalized due to fractures.

Anne also explained that, after puberty, individuals with OI experience a period during which the prevalence of fractures decreases. However, with advancing age, bone strength decreases, precipitating an increase in the frequency of fractures. Anne indicated that, over the past three to four years, she has experienced an increase in the number of fractures.

In addition to bone fragility, OI is associated with other characteristics and complications. In particular, Anne outlined a few of the additional characteristics she has, including shortness of stature, abnormal tooth development, and curvature of the spine. Anne mentioned that the growth pattern of her skull was also affected. Most noticeable is the significant flattening of the back of her head, which Anne believed is the result of the considerable amount of time she spent lying on her back as a baby. Another aspect of the disability that Anne manages is chronic pain. Although there is



no cure for OI, combined treatment using medication, surgery, and rehabilitation therapy has improved functional outcomes.

Anne relies on a power wheelchair for mobility and commutes using a public transportation service designed for individuals with disabilities. Anne also requires the aid of personal assistants for personal care, as well as the completion of domestic tasks, including cleaning her apartment, shopping, and caring for her three cats.

Anne remembers that, in spite of her disability, her parents had the same expectations for her as for her siblings. Anne described one incident in which she deliberately misbehaved, telling her mother, “Well, you can’t hit me. I know you can’t hit me because you’re gonna break me.” Anne reflected, “I was using my disability to get away with murder, so to speak,” and she presumed that her mother would not discipline her because of her disability. Notwithstanding, her mother gave Anne “a little swat on the cheek” and declared, “Enough is enough and this is who you’re gonna become and we’re just gonna raise you the same as anybody else in the family.” At the same time, however, Anne stated that there were those in the medical profession who were unsupportive of her parents’ efforts. Anne related that several physicians advised her mother, “You know, to be fair to your other children, you really should put her in an institution. It’s not right to have her around the regular children.”

Anne is currently a registered psychologist assistant. At one point during the interview, she asserted, “You are what you make of your life—not what life makes of you.” Prior to entering this profession, Anne completed a Bachelor of Education whereupon she realized that, physically, she was not capable of pursuing a career in



teaching elementary school-aged children. Thus, Anne finished a Master's degree in educational psychology. She presently works part-time for a neuropsychologist who specializes in counseling individuals with disabilities and those who are in chronic pain. Anne also serves on the board of directors of an organization which assists individuals with disabilities in obtaining competitive employment.

### Charlotte

Charlotte is 54 years old and, like Anne, has *osteogenesis imperfecta* (OI). However, unlike Anne, although Charlotte was born with several bone fractures, physicians were unable to diagnose her disability until she was five years old. Charlotte believes that the physicians' inability to identify her medical condition at birth was due to the rarity and relative unfamiliarity of OI in the 1940s. Charlotte further explained that her mother's pregnancy was perceived as normal and that the birth of a baby with a disability was "totally unexpected to the attending doctor, never mind my family. It was a terrible, terrible shock for my family."

In discussing her disability, Charlotte described several principal characteristics of OI. She mentioned that she has had countless fractures—"probably six, seven to eight hundred breaks or fractures"—since birth. To illustrate the significant weakness of her bones, Charlotte revealed that she feared balloons because the unexpected popping of a balloon would cause her to jerk suddenly and consequently fracture a bone. During her adolescence and young adulthood, like Anne, Charlotte did not have any fractures. Similarly, Charlotte has shortness of stature and bowing of the legs. Although bowing of the legs is often treated with surgical straightening, Charlotte explained that the procedure could not be performed





on her because of the severe reduction of mineral density in the bones of her legs.

Even though she was fitted with orthotics to assist with mobility, Charlotte recalled that she never walked:

I used to scuttle around on my behind until I got my first wheelchair when I was seven and this thing scared me half to death. I would rather let my big brother take me to school in his little red wagon in summer and the sleigh in winter.

However, Charlotte remarked that her mother insisted that she learn to use the wheelchair, and Charlotte now relies on a power wheelchair for mobility.

While Charlotte and Anne share common characteristics of OI, Charlotte has had to manage other complications unlike those of Anne. As a newborn of three months, Charlotte developed hydrocephalus, a condition characterized by abnormal accumulation of fluid within the cavities of the brain; in infants, this leads to enlargement of the head. Hydrocephalus is not necessarily associated with OI, and the specific cause of the condition in Charlotte's case is unknown. Although individuals with hydrocephalus are usually treated with a shunting procedure, Charlotte explained that it was not available at that time. However, for unaccountable reasons, the fluid drained away from her brain. Charlotte reflected, "I really think it was a miracle."

Charlotte has also been diagnosed with progressive hearing loss, an impairment which occurs in approximately 50% of individuals with OI. Charlotte expressed, "I call myself 'double disabled' because I'm physically disabled and auditorily disabled. I would say that my hearing loss has been much more crippling for me psychologically than being in a wheelchair." Charlotte believes that the age of



onset of her hearing impairment was five years, although it was not identified until she was seven years old. At that time, Charlotte was fitted with earmolds and behind-the-ear hearing aids. However, because of the progressive nature of her hearing impairment, at the age of 18, physicians attempted to treat her hearing loss surgically. Unfortunately, it was not successful, partly due to her OI. Subsequently, Charlotte was fitted with a bone conduction hearing aid. Charlotte exclaimed that the bone conduction aid provided her with significant amplification: “I heard sounds I’d never heard before, such as the wind blowing in the trees or things frying in a frying pan.” Charlotte currently continues to use the bone conduction hearing aid, although she indicated that it is no longer beneficial. Recently, Charlotte was a candidate for cochlear implantation. However, she was informed that her skull is too thin to undergo the surgical procedure. She is presently in the process of learning sign language.

It should be mentioned that Charlotte’s hearing impairment did not hinder the interview process, in part because she was provided with a written version of the interview guide to which she could then respond orally. It was noted, however, that the lighting in Charlotte’s apartment was dimmed so that Charlotte could be alerted by the flashing of the lights when the telephone rang or someone was at the door. In addition, Charlotte uses a TDD, or a telecommunications device for the deaf.

Charlotte lives independently in the community, even though she disclosed, “When I lived at home, I was not allowed to do anything.” She explained that she is the second youngest child of six siblings and commented that she “came from a very sheltered home.” Nevertheless, Charlotte stated that she currently prepares her own



meals and for many years had done her own cleaning and shopping. Charlotte voiced displeasure that she must rely on assistance from others at times, such as when she is immobilized because of a fracture: “I really notice the lack of independence. It’s very hard on me. I’m like a bear in a cage or whatever, a bull in a china shop. I get very cranky.”

Charlotte is currently engaged in full-time studies and is completing a certificate program in social work. She is considering the possibility of pursuing a second undergraduate degree in the same area. Charlotte commented that making the transition to university was quite challenging. At the same time, she stated, “Even at times when I was scared to death, I never let the disability stop me.” Following the completion of her first undergraduate degree in education, Charlotte worked as a secretary and also did volunteer work with children in a residential pediatric rehabilitation facility and with senior citizens in an extended care facility.

### **George**

George is 22 years old and has Duchenne muscular dystrophy (DMD), the most common form of muscular dystrophy. DMD is a hereditary disease characterized by progressive muscle weakness caused by the degeneration of muscle fibers.

Specifically, DMD results from a mutation in a particular gene which causes decreased production or absence of dystrophin, a protein necessary to stabilize the muscle membranes during contraction. This deficiency in dystrophin results in muscle degeneration. Moreover, the muscles (principally the calf muscles) develop pseudohypertrophy as a consequence of the gradual destruction of muscle fibers.



Pseudohypertrophy, which literally means false excessive growth, gives individuals like George the outward appearance of relative health and strength, when in fact the muscle fibers are being replaced by fat and fibrous tissue. DMD affects all muscles, including those of the heart and diaphragm, often leading to heart and respiratory failure, and early death.

As a hereditary disease, DMD is passed between generations by mothers who carry the abnormal gene, which affects only male children. George reported that his mother was aware of being a carrier of the abnormal gene and that he had two maternal uncles with DMD. Nevertheless, George's parents were unaware of any problem until he was three years old and had developed a waddling and unsteady gait. Subsequently, a muscle biopsy was performed, revealing DMD.

Individuals with DMD often require the use of a wheelchair by early adolescence. George stated that he "became permanently in a wheelchair when [he] was about ten years old." At the time of the interview, George commented that he was in the process of acquiring a wheelchair which could be tilted back to take the weight off his hips, to relieve his pain. Although the wheelchair has been essential for maximizing mobility and function, it has not necessarily enhanced George's independence. George expressed frustration at not being able to use public transportation, despite its accessibility, because of his need for specialized wheelchair restraints and supports: "You can get on them, but someone like me that has poor balance, the buses are pretty much very dangerous because I'll be flopping all over." George's parents have hence purchased a van equipped with the necessary restraints and supports. However, George further disclosed that while the van has allowed for





more community mobility, the extent to which he is able to participate in activities is dependent on the availability of someone to drive the van.

This issue of mobility, limiting George's independence, is perhaps ironic in that five years ago, George moved to the city because he was "kinda starting to get bored living in a town of only 200 people." At that time, George moved out of his family home to a group home in the city where he met his wife. Subsequently, George and his wife moved to an apartment, where they now reside with the aid of personal assistants.

George requires personal assistance to complete basic activities of daily living such as bathing, dressing, and eating, as well as other tasks he cannot do on his own, including house cleaning and preparing meals. While George currently employs home care nurses to provide personal care, he recounted that when he was in high school, he had to "rely on students to help [him] go to the washroom." George voiced further dissatisfaction with the insufficient supportive services available in high school that perhaps discouraged him from completing his secondary education. At one point in the interview, George reflected, "If I wasn't disabled, I'd be able to do a lot more, (pause) [I'd be] more likely to pursue a proper education and employment."

### **Madeline**

When Madeline was asked about her disability, she responded by stating that the medical term for her disability was spinal muscular atrophy (SMA). Madeline continued, "I call it an 'oops!' of nature. I think it was just a chromosome 'oops!' when my mom was pregnant." Madeline was not diagnosed with SMA until she was two years old. Because it was in the 1950s, Madeline recounted that physicians



initially thought she had polio, which is caused by a virus that also selectively destroys nerve cells in the spinal cord. However, as time progressed and Madeline did not positively respond to the prescribed treatment for polio, physicians deduced that Madeline must have a different neuromuscular disorder. Madeline recalls that, at that time, little was known of SMA and her parents were informed by the physicians, “Oh, well, she’ll die by twelve.” Madeline is now 49 years old.

SMA is a congenital neuromuscular disorder associated with progressive muscle weakness resulting from abnormalities of anterior horn cells. Anterior horn cells are nerve cells in the spinal cord which play a critical role in carrying nerve impulses between the brain and the muscles, allowing movement to occur. Individuals with SMA, like Madeline, have severely decreased numbers of these nerve cells throughout the brainstem and the entire length of the spinal cord. Consequently, affected muscles lose their tone and strength, after which the muscles begin to shrink, or atrophy. As a result, both voluntary and reflexive muscle movements are reduced. Madeline’s muscles have weakened to the point at which she must now rely on a power wheelchair for mobility. However, she remembers being able to walk without assistance until she was 12 years of age. At that point, Madeline obtained her first traditional manual wheelchair, although she was capable of walking behind it until she was in her early twenties. While the wheelchair provided Madeline with independence and mobility, it was also a factor in preventing her from completing her secondary education because of inaccessibility: “I couldn’t go to high school ’cause the school was full of stairs and I used a wheelchair.” At the same time, Madeline’s dependence on a wheelchair for mobility did not deter her



from becoming involved in social activities. For instance, Madeline related that she has traveled internationally and has participated in many sports such as wheelchair square dancing.

Although weakness in the legs is generally greater than weakness in the arms for individuals with SMA, the researcher observed that Madeline did not have the use of her hands. For example, Madeline used her tongue to lift a piece of paper from the kitchen counter, and she used a pen held between her teeth to push the speaker button when answering the telephone. Madeline also used a straw when drinking her soda, as she was unable to grasp and lift the can to her mouth.

Madeline has also required more personal care as her disability has progressed. Up until five years ago, Madeline lived independently, requiring only domestic help. She currently lives in an integrated housing cooperative in which approximately half of the suites are designed for individuals with disabilities. The housing cooperative also provides some supportive services, including personal care assistance, which Madeline now requires.

Unlike muscular dystrophy, spinal muscular atrophy does not affect the heart muscle. However, chest and respiratory muscles may be affected, causing breathing difficulty. Madeline mentioned that the capacity of her respiratory system had decreased considerably during the past three years, diminishing her stamina. As a result, she is no longer capable of employment. As she explained, “I did a medical retirement three years ago.” Prior to “retiring” three years ago, Madeline was an instructor in a training program which assisted physically disabled individuals to learn independent living skills. Although Madeline’s “retirement” was precipitated by the





progressive nature of her disability, it has not been, in her words, “a factor for me to sit around and be bored.” Madeline continues to be an active volunteer, serving on various boards of directors and organizations related to disabilities.

### **Peter**

Peter’s profile parallels that of Madeline in that Peter also has spinal muscular atrophy (SMA). Peter, who is 46 years old, was diagnosed with SMA when he was three to four years of age. Peter recounted that his parents first became concerned when the development of his gross motor skills were significantly delayed. As an infant, Peter was only able to take a few steps while holding onto furniture, whereupon he would fall and slide himself on the floor. Because it was in the 1950s, Peter’s parents, like Madeline’s, were also initially told that he had polio. Similarly, when diagnosed with SMA, Peter’s parents were informed that he would most likely not live beyond puberty.

Throughout the interview, Peter mentioned the importance of the support he received from his family. At the same time, Peter disclosed that, as a child and later as an adolescent, he felt that he “missed out on a lot.” Peter revealed that he had minimum interaction with his peers, especially as he did not go to school. He completed his education to grade 11 through correspondence; as he reflected, “All my schooling was done from my bedroom.” Also, because of limited wheelchair accessibility in the community, Peter related that he had few opportunities to participate in recreational activities. Moreover, what opportunities he had were further restricted by the season: “So winters would come and I’d basically be stuck inside until spring.”



Although Peter did not complete high school, he was able to pursue a career as a commercial artist. However, because of the progressive nature of SMA, he indicated that “every year, I lose more and more strength.” Thus, Peter is no longer capable of performing tasks requiring fine motor skills, and he is not currently employed. At the same time, he stated that, while he is now interested in becoming a webmaster or a computer researcher, engaging in such work depends on his acquiring a computer with the necessary adaptations, including voice recognition and a tracker mouse. In the meantime, Peter actively volunteers with organizations whose activities are related to disabilities.

While Peter’s childhood was characterized by limited contact with the community, at present Peter lives independently with the aid of personal assistants who help him bathe, dress, eat, and perform other tasks he cannot do on his own. Approximately 20 years ago, Peter moved out of his family home because of the expected difficulty his parents would face in providing him with adequate care as they aged. Initially, he entered an extended care facility and later transferred to a group home. Peter summarized his experiences living in the two residences by stating that living with eight other individuals in the group home was preferable to living with 200 individuals in the extended care facility. Subsequently, Peter became involved in a pilot project through which he came to live in his current residence of more than 11 years: a housing cooperative in which approximately half of the suites are designed for individuals with disabilities. The housing cooperative also provides various support services, most of which he requires. Peter appreciates the independence he



has attained in adulthood and, since the interview, the researcher has observed him frequenting cafés in the community. Perhaps the following quote summarizes it best:

Just to live in the community as I am, with somebody with the level of disability I have, to me, I'm very fortunate to have that opportunity. I never thought when I was younger that I would ever be able to live in this type of setting—in an apartment, in a community. I thought I'd probably be in an institution.

### Alice

Alice is 37 years old and has cerebral palsy (CP). CP is a developmental disability that results from damage to or dysfunction of the brain before it has fully developed. Critical stages of the brain's development occur during the prenatal period and early childhood. Events or conditions which interfere with the typical developmental process can result in a set of motor abnormalities and functional impairments referred to as cerebral palsy.

CP may result from numerous conditions. Although previously it was thought that most cases of CP resulted from adverse complications during labor and delivery, current research indicates that only a small fraction results from such conditions. However, Alice's birth was traumatic. She related that the umbilical cord was compressed between her head and the birth canal, necessitating emergency cesarean delivery. The excessive pressure on the umbilical cord restricted the circulation of oxygen and blood to Alice's brain, resulting in CP.

Like all individuals with CP, Alice has problems with movement and posture. She relies on a high-backed power wheelchair with specialized supports and commented, "This is all I've known 'cause I've been this way since the day I was born so I don't know any other different." Accordingly, Alice requires personal



assistance to complete basic activities of daily living such as bathing, dressing, and eating, as well as other tasks she cannot do on her own. Many individuals with CP also have other disabilities associated with damage to the central nervous system. The impairments associated with CP are nonprogressive, but permanent. Specifically, Alice has a speech impairment. She expressed indignation that, because of her speech disorder, “people think that I’m mentally disabled, as well and they talk to me like I’m mentally disabled, and I’m not.” Alice also indicated that she has had seizures since she was three months old.

When she was five years old, her parents brought Alice to the city and placed her in a hospital offering residential pediatric rehabilitation services. Alice recounted that she grew up in the hospital, and in addition to physical and occupational therapy interventions, she attended the education program in the hospital. Alice reported that, although she completed her education to grade 10, assessment results indicated that her performance reflected a grade equivalent of 7.0. Several times throughout the interview, she voiced disappointment with her education experience stating, “The only thing I wish is that so-called educators would have helped me out more with my education.”

Moreover, in describing her experience of living in the hospital, Alice revealed that she felt she “missed out on the so-called normalcy of family life.” At a later point during the interview, Alice reflected,

I was kind of put away in an institution, not being able to, (pause) instead of having quote, unquote, a ‘normal’ life. And even though I found I interacted with people all the time, I was alone and didn’t have friends.





When she reached the age of 18, when one is no longer eligible to reside at the hospital, Alice was transferred to a group home. Alice recalled that this transition to living in the community was a challenge, as she had been raised in a segregated setting: “When it came to, you know, being out in the community, I was kind of lost.” However, it was in the group home where Alice met George and they are currently married and living together in an apartment.

### **Heidi**

Heidi is 39 years old and, like Alice, she also has cerebral palsy (CP). However, Heidi developed CP as a result of brain damage caused by complications resulting from the incompatibility of her blood type with that of her mother. Although a baby’s and mother’s circulatory systems are separate, it is possible for the baby’s blood cells to enter the mother’s circulation. When a mother’s blood group is Rh-negative and that of her baby is Rh-positive, the mother’s immune system perceives the baby’s red blood cells to be foreign. Accordingly, the mother’s immune system forms antibodies that cross the placenta to the baby and begin to destroy the baby’s red blood cells. This leads to a condition in which the baby’s oxygen supply is drastically reduced, and a toxic accumulation of bilirubin (a waste product that is released when red blood cells die) develops.

At birth, Heidi’s mother was informed that Heidi would die and that “there [was] no hope.” However, when Heidi’s mother stated that she believed that her baby would live, the physicians acquiesced, commenting, “Well, she’s going to be a vegetable.” Today, Heidi is married to a person who is not disabled. She is the mother of two children, an eleven-year-old girl and an eight-year-old boy.



Intensive habilitation, including speech, physical and occupational therapy, has played a significant role in maximizing Heidi's functional mobility and enhancing her participation in the community. Heidi has also had 11 surgical procedures. She indicated, "Until the age of seven, I walked on my knees." Subsequently, Heidi developed the ability to walk, although it was not without a gait disturbance. Now, however, Heidi relies on a power wheelchair for mobility as a result of a hip dislocation due to her pregnancies. Heidi recounted that an orthopedic procedure was done to ensure that her hip joint remained functional. Nevertheless, her pregnancies negated the effectiveness of the surgery, impairing her ability to walk. Heidi also remarked that she is now able to speak because of speech therapy, even though she still has slight difficulty with articulation.

Like Alice, Heidi attended a segregated education program directed by a hospital offering pediatric rehabilitation services. However, in grade nine, Heidi was placed in an inclusive education program. Heidi recalled that this transition was difficult: "Everybody stared at me—how I was walking—and they made fun of me. And I came home from school crying my eyes out." She proceeded to mention that one of her teachers "took [her] under his wing and taught [her] how to live with the nondisabled people because if you're going into this society, you have to toughen up." Heidi continued her education through grade 11 and later completed several grade 12 courses, as well as computer and secretarial training.

Although Heidi has pursued computer-related employment in the past, she is presently a full-time mother. She took pleasure in talking about her children, describing that they "bring [her] joy." Heidi also expressed appreciation for the



support and personal assistance she receives from both her children and her husband.

Heidi commented that, while her pregnancies resulted in the loss of her ability to walk, “[she] would do it again.” At the same time, she disclosed, “Sometimes I wish I could walk with them in the field, . . . but I can’t do that.”



Seven participants with various disabilities have been profiled in this chapter. All the participants were born with disabilities which have had a significant impact on their lives. These profiles provide the background and context for understanding the participants’ perspectives concerning decisions about the medical treatment of newborns with disabilities, which is the focus of the following chapter.





## **CHAPTER FIVE**

### **THE PARTICIPANTS' PERSPECTIVES**

The seven participants profiled in Chapter Four shared their perspectives concerning decisions regarding the medical treatment of newborns with disabilities. As discussed in Chapter Three, the participants' responses to the interview questions were analyzed for descriptions, patterns, themes, and relationships. Analysis of the data resulted in the identification of the following three overarching categories within which the extracted themes were organized.

- Making Treatment Decisions in Newborns' Best Interests
- Procedural Aspects of Making Treatment Decisions
- Criterion Factors in Making Treatment Decisions

The first category centered solely on the theme of making treatment decisions in the best interests of newborns. Within the second category, procedural aspects of making treatment decisions, two themes emerged, focusing on surrogate decision-makers and informed decision-making. The third category, criterion factors in making treatment decisions, consisted of three subcategories within which various themes were identified. The first criterion, ethical principles, included the themes of personhood, the sanctity-of-life ethic, and the principle of the quality of life. The second criterion, clinical features, incorporated themes focusing on the type of disability, the extent of disability, and prognosis. The third and final criterion, external measures, explicated the themes of financial considerations and social support. (See Appendix C for an overview of the participants' perspectives.)



## Best Interests

### Best Interests

A primary consideration in making decisions regarding the medical treatment of newborns with disabilities should be what would most likely promote the newborn's well-being. However, determining what is in a baby's best interests is not necessarily straightforward. The potential exists for one person to perceive the best interests of a baby differently from the way in which they are perceived by others. Without exception, the participants commented on the complexity of making treatment decisions in the best interests of newborns with disabilities. While all the participants thought that it is usually preferable to administer and maintain medical treatment, several acknowledged that there may be circumstances in which decisions to withhold or withdraw medical treatment are in a baby's best interests.

Of the seven participants, Madeline, Peter, and Heidi challenged the withholding or withdrawal of medical treatment in the best interests of newborns with disabilities. They perceived that decisions to withhold or withdraw medical treatment may claim to be in the best interests of a baby, when, in fact, they are in the best interests of other persons. Peter deemed such reasoning as an ineffective attempt to rationalize abdication of responsibility:

I think that's just an easy way out. How can it be in their best interest? It's because they maybe aren't able to cope with it or handle it themselves. . . . I think it's just an easy out. (Peter)

Baby's sake??? . . . They can't withhold treatment. They should use better discretion. They shouldn't withhold [treatment]. They should try first. If they didn't try on me, I might have not been here. (Madeline)



On the other hand, Anne, Charlotte, George, and Alice remarked that there may be conditions in which decisions to withhold or withdraw medical treatment are in a baby's best interests.<sup>7</sup> However, Charlotte specifically emphasized that she “would have to assess each case individually to make a decision.”

Further, Anne expressed concern for ensuring the best interests of newborns in cases where the withdrawal of medical treatment is recommended, despite the parents' desire that medical treatment be maintained. In such circumstances, Anne thought that parents should consider whether or not their unwillingness to consent to the cessation of medical treatment promotes the baby's or their own interests:

It may be hard for parents, but I think that's where a psychologist or somebody like that, a minister, whatever, can help them take a step back and say, “Listen, are you keeping your baby alive for you or are you keeping your baby alive for the baby's sake?” . . . They need to step back and think of that and if they think—if they feel—that they're really keeping the baby alive for their own sake rather than for the well-being of the child, then I think that's a criterion they need to take into consideration. And if it's for themselves and the baby is really just gonna spend most of their life in the hospital of what short life they have, maybe it would be better to let nature take its course and just take all treatment away and let them go when it's time.

Anne stated that, in the aforementioned situation, the withdrawal of medical treatment is not only in the baby's best interests, but also in the parents' interests. Anne recommended that parents consider their own psychological well-being and that of the newborn's siblings. At the same time, she suggested that parents should not have misgivings if they make the decision to abate treatment:

For your own mental health and your other family, you know, whether you have other children or not, you may need to let the child go. I mean, you may think you're being cruel, but maybe in the long run, you're helping all yourselves out (pause) because you will never forget your baby. That baby will always be a part of you and will always be a part of the family. But you may need to let them go and to accept that and that to do so isn't wrong.



Clearly, making treatment decisions in the best interests of newborns with disabilities is complex and perhaps contradictory. Although all the participants generally preferred the administration and maintenance of medical treatment, several also recognized that there may be cases in which the withholding or withdrawal of medical treatment is in a baby's best interests. At the same time, however, a "best interests" standard does not identify who should be responsible for determining what is in the best interests of newborns or define criteria for making treatment decisions. Accordingly, there is a need to address both the procedural aspects and criterion factors in making decisions regarding the medical treatment of newborns with disabilities.

### **Procedural Aspects**

#### Surrogate Decision-Makers

The principle of patient autonomy with regard to decisions concerning medical treatment requires that the expressed preferences of patients be respected. However, babies cannot express preferences or participate in the decision-making process; decisions concerning the medical treatment of newborns with disabilities must be made by others. This raises the question of *who* should make these treatment decisions. Although the participants' responses varied, they collectively proposed four classes of decision-makers for newborns with disabilities: parents, physicians and other health care professionals, ethics committees, and courts.

Parents. The participants all concurred that parents should generally be the primary surrogate decision-makers for newborns with disabilities. They believed that





parents are the individuals most committed to act in the baby's best interests.

Furthermore, parents would be responsible for the care of the baby:

I always think that the parents should be involved. . . . And that the decision—as a final judgment, as an absolute final—should in all likelihood come up from the parents. . . . Let the parents make that choice themselves because they are the ones who brought the little one into the world. They are the ones who are responsible. (Anne)

Heidi made a distinction between the roles of mothers and fathers in making decisions regarding the medical treatment of newborns with disabilities. She specified that the mother alone should make the treatment decisions for her baby:

I think the mother is the closest to the baby. . . . At birth, the mother should say, "Please do it or please do not do it." . . . Because if it just came out of you, you're still connected to the baby, one-to-one, you know. But if it's a year or two years old, the father can come in because he knows the child, too.

Other participants mentioned that in circumstances where parents are unable or unwilling to make treatment decisions for their baby, the closest family member or guardian should be given the decision-making role:

Well, first off, for me, would be the parents, if they are functionally able to do that. Whereas, if you have, say the druggie or—I mean, it depends on the circumstances, too. Say you have someone that has a mental disability . . . or say it's a rape case kind of thing. It should be either the parent or the closest relative that's fit to make a decision. (George)

The person who's responsible for looking after the baby has to make those decisions . . . whoever the guardian is—if that be the parent or the social worker or the foster situation. (Peter)

While parents were favored as the primary decision-makers for newborns with disabilities, most participants also indicated that treatment decisions should not be left solely to parents. As Madeline commented, "There's a number of other factors that the parents may not know of." However, acknowledging the involvement of others in the decision-making process was more difficult for some participants than others.



Alice, in particular, was reluctant to support the inclusion of other decision-makers in addition to a baby's parents and family members. Alice's uncertainty seemed to result from a concern for the baby's future care as she reflected on her own childhood experience:

In a way I agree and in a way I disagree 'cause I mean, like, the way I grew up, it made me feel if the person was alive, then ship him off to [name of hospital] where they had no family, no nothing and they've been seeing all these young kids who had parents and brothers and sisters coming to see them or whatever and they didn't have that. They didn't really have anybody, you know. It was maximally hard, you know, for them to grow up that way.

The participants who advocated for the involvement of others in making treatment decisions suggested physicians and other health care professionals, ethics committees, and courts as additional surrogate decision-makers for newborns with disabilities.

Physicians and other health care professionals. With the exception of Heidi, all the participants supported the involvement of physicians in the decision-making process concerning the medical treatment of newborns with disabilities. As mentioned previously, Heidi believed that only mothers are qualified to make treatment decisions for their babies. Heidi expressed a lack of confidence in physicians' abilities to make accurate diagnoses of the medical condition of newborns with disabilities:

No, because they [physicians] can do "oopsy!" They can diagnose it wrong and say, "Oh, I did it wrong. I'm sorry." . . . So I don't think they should be allowed to have that authority of saying, "Oh, we should do this."

The participants who advocated the involvement of physicians in making treatment decisions stated that the inclusion should not be limited to physicians only. They emphasized that other health care professionals should also be a part of the decision-making process:



And not only just doctors, but therapists. Like, there's physio and occupational, and the whole spectrum of rehab for treating people with disabilities. (Peter)

Concerning the role of physicians and other health care professionals, the participants indicated that their purpose is not necessarily to act as surrogate decision-makers for newborns with disabilities. Rather, physicians should support and assist parents in making treatment decisions for their baby, specifically by providing all relevant medical information:

[Physicians and other health care professionals] should be available to provide accurate information. (Madeline)

Furthermore, Anne, in particular, thought that, in accordance with their moral obligation to treat illness and preserve life, physicians should support parental decisions, even if medical treatment for a baby is considered futile:

I feel if a doctor takes an oath to take care and provide and you know, heal, then they should do that even if it's against their better judgment. The parents are the ones who love that baby. I mean, the doctor remains fairly detached, but a parent's heart and soul is in that baby and I think doctors, nurses—any type of medical professional—need to respect that a little bit more.

Anne further commented that, should physicians be unwilling to provide medical treatment, they should nevertheless be obligated to help parents make other arrangements for obtaining medical treatment for their baby:

I guess hospitals can refuse to offer service, but then it's up to the medical people and to allow the parents to find another place that may offer medical service.

Even though the participants advocated that physicians and other health care professionals should play a supportive role in the decision-making process, they also mentioned that there may be circumstances in which physicians may be required to intervene and act as surrogate decision-makers for newborns with disabilities. As a





case in point, Charlotte and George observed that, in situations where there are no available family members willing to be a baby's surrogate decision-maker, treatment decisions for the newborn should be the responsibility of physicians:

If there is no way to have family involved, . . . and there's no one—there's no immediate family—then it kind of has to be the decision of the doctor.  
(George)

Another situation in which physicians may be required to intercede was also suggested by George. He referred to circumstances where physicians believe that the decision made by parents to withhold or withdraw medical treatment cannot reasonably be judged to be in a baby's best interests:

Well, maybe if the family is making a completely pointless decision, . . . then the doctor should have the say.

While most participants were satisfied with the contribution of physicians and other health care professionals in the decision-making process, a few participants considered additional approaches, including ethics committees and courts in making decisions regarding the medical treatment of newborns with disabilities.

Ethics committees. Although not all the participants referred to the involvement of ethics committees, three participants, Anne, Charlotte, and Madeline, advocated that decisions concerning the medical treatment of newborns with disabilities need to be made not only by parents with the support of physicians, but also with the facilitation of ethics committees:

I think that unfortunately, I think a lot of times it's left to just the doctor and the parents, and nobody else is allowed to be involved. . . . And I don't think it can be . . . . So it should be a total system. (Madeline)

Anne, Charlotte, and Madeline believed that ethics committees serve an essential function in the decision-making process. Ethics committees were seen as a



means by which to support and counsel parents in making treatment decisions for their baby, in addition to the medical knowledge and clinical experience of physicians. Ethics committees were also viewed as having the capacity to act as intermediaries to resolve conflicts that may arise between parents and physicians:

The parents have to have a support system to be able to cope with the long-term effects. (Madeline)

People in different specialties need to get involved to emotionally help guide the parents through it [the decision-making process] because it's a very emotionally tough time. I mean, your child's just been born with a disability. You're already trying to cope with that and then now, you've got doctors coming at you. . . . How can you handle that when you're just trying to cope with having a baby with a disability? And so counseling and having a mediator, like, maybe a psychologist, social worker, or somebody like that may be good as part of the team. (Anne)

Anne, Charlotte, and Madeline suggested that ethics committees should consist of multidisciplinary panels. They recommended that ethics committees should be comprised of the following members:

- (a) a social worker,
- (b) a psychologist or psychiatrist to assess and help clarify the preferences of parents:

There should be a psychologist or psychiatrist in there also because the parents need to be assessed. There would be a test to decide whether they had the capabilities to cope, whether they want to [withhold or withdraw medical treatment] or not. (Charlotte)

- (c) an individual with expertise in bioethics,
- (d) a member of the clergy to address religious issues that may be critical to parents:

You would have to bring a clergyperson into this because, again, it's a life and there can be religious ramifications to the decisions that are made. (Charlotte)



- (e) a representative of an association of the appropriate disability to provide information about social support and resources available to parents:

For instance, if it is a Down syndrome child, and they know that, a Down syndrome association should be there to help, you know, say, "This is what's available to you. These are the supports." (Madeline)

The women thought that a diverse membership on an ethics committee would provide parents with a well-rounded opinion to assist them in making decisions regarding the medical treatment of their babies. At the same time, a couple of participants indicated that there may be circumstances in which the decision-making process is threatened by legal difficulties, and thus requires the involvement of the judicial system.

Courts. Two participants addressed the involvement of courts in the decision-making process. Charlotte supported the participation of the courts in the decision-making process because of possible legal implications of life and death decisions:

Lawyers do have to be involved because the hospital, the ethics committee, the parents, the attending medical specialist, they could be affected legally by the decisions that will be made to withdraw life[-sustaining treatment].

At the same time, however, Charlotte conveyed regret at the need to resort to the courts in making treatment decisions for newborns with disabilities:

It's too bad you have to even care about the legality because it can make things much more difficult, much more painful. But for the protection of those involved, yes, they definitely have to be there.

On the contrary, Anne did not perceive the judicial system to be an appropriate recourse in making treatment decisions. She expressed anxiety concerning judges acting as surrogate decision-makers for newborns with disabilities, particularly because of their lack of medical expertise:





Judges make horrible decisions at times and how can they sit there and make a judgment when they don't have any medical background and they're reading a medical report and they may or may not understand what is at stake? And so how can they sit there and judge when they're not understanding all of the facts?

Even though the participants presented opposing viewpoints, the involvement of courts was acknowledged in making decisions regarding the medical treatment of newborns with disabilities. However, in contrast to the roles of physicians and other health care professionals, and of ethics committees, the participants regarded court involvement in the decision-making process as intervention rather than support.

On the whole, the participants generally agreed that decisions concerning the medical treatment of newborns with disabilities should not be made exclusively by one individual or group of individuals. Parents were regarded as the first choice as surrogate decision-makers, with physicians and other health care professionals, ethics committees, and courts participating in the decision-making process to varying degrees. Nevertheless, regardless of who makes the treatment decisions on behalf of newborns with disabilities, the participants stated that there is a need to ensure that any decisions are well-informed.

### Informed Decision-Making

The participants identified a need for surrogate decision-makers to be well informed. They expressed concern that without adequate information, surrogate decision-makers may be led to make treatment decisions which reflect a lack of understanding and are not judged to be in the best interests of the baby:

Well, my question would be, if this person is well informed or are they just seeing this disabled baby and like, saying, "kill it" kind of thing. Maybe they don't know what they're talking about. Maybe this kid is just convulsing because it has CP [cerebral palsy]. But once it's through that stage, it will be





able to function as a normal child even though it may have a speech impediment or walking difficulties. . . . If the person knew about CP, they'd probably be like, "Well, give the baby some time." Whereas someone who's uninformed might just be like, "Why keep it alive?" kind of thing. (George)

Moreover, the participants believed that both physicians and parents should share the responsibility for making informed decisions regarding the medical treatment of newborns with disabilities. The participants deemed it imperative that physicians provide full medical information to parents concerning their newborn and the medical treatments available. At the same time, the participants considered it equally important that parents take initiative to obtain the necessary information to make informed decisions.

Physicians' responsibility. All the participants believed that it is the responsibility of physicians to provide complete and accurate information to parents concerning the medical condition and expected prognoses of their newborns. In addition, they thought that physicians should outline the nature and purpose of medical treatments, including the risks and benefits, alternatives, and recommendations:

They [physicians] better have the proper information and research it as much as they can. (George)

It is very important for medical professionals to sit down with the parents and let them understand what exactly is happening to their baby. . . . To make sure that they have every piece of information needed to make that final choice. . . . What's happening, what's wrong, what may happen in the future, what exactly they feel the future hold for them and the baby, itself. (Anne)

Many participants held the opinion that physicians should not only provide parents with the necessary medical information, but also present parents with information related to coping and caring for babies with disabilities:



The role of the doctor is to deliver and provide the medical care needed and *also* [emphasis added] to be informed himself on the options, on what's available in the community for people with disabilities or parents of people with disabilities, support groups, the education system which is now a lot more integrated than it was, the group homes, and so on and so forth. (Peter)

However, several participants observed that many physicians are not as informed as they should be. Anne, George, and Alice viewed some physicians' knowledge of disabilities in general as wanting:

I've found that even in the hospital, a lot of people are ignorant on what the disability is. They automatically assume you've either been in an accident or you have MS [multiple sclerosis]. I've been stuck in the hospital, sitting after surgery with them thinking I have MS and not doing anything for me and there I'm stuck. Like, I don't have MS! (George)

Although, in a previous quote, Peter remarked that physicians should be able to provide parents with information about services related to coping and caring for babies with disabilities, he perceived physicians as lacking awareness concerning non-medical issues:

A lot of doctors don't have a clue when it comes to this sort of thing because they're coming from a medical side.

Accordingly, the participants advocated a need for physicians to collaborate with other health care professionals. They expressed the belief that physicians should consult with other professionals to broaden their own understanding of disabilities and medical treatment options, thereby leading to more informed decision-making:

Don't just assume because your capabilities don't allow you to do a procedure or you don't have the understanding of what is wrong with that child, don't just stop there. Investigate, phone, talk, learn from other professionals because we can all learn from each other. There's a whole world of medical professionals out there and, as a doctor, you have access to that. (Anne)

And when I was talking earlier about doctors getting in touch, I mean, he [the physician] even phoned the Toronto's children hospital and talked to different doctors in Toronto to get advice. He said, "Okay, this is the difficult case that



I have,” and talked to other doctors who have dealt with children with my disability and asked them for advice. Like, he didn’t just say, “Oh, I know it all.” He reached out and got further information. (Anne)

The participants also addressed the need for physicians to assist parents to make informed treatment decisions for their newborn by establishing a relationship which fosters understanding rather than approaching them with paternalistic attitudes. The participants stated that physicians need to communicate in a manner that reflects the dignity and respect parents deserve:

Please listen to the parents. . . . Don’t be negative to the parents. (Heidi)

This is where the medical professionals, I feel, fall down. They speak in medical terms rather than plain English and they just need to start sitting down with parents and sit with them and explain. And like I say, in plain English. . . . Be more respectful to the parents. Learn to talk to parents as equals rather than talk down to them. . . . Respect the fact that that is their baby. That is a part of them and don’t dismiss it as an “it.” They will have probably named it. *That* is the baby’s name. Don’t just come and say, “Baby-so-and-so,” or “Baby-this.” Come in and say the baby’s name. And don’t talk to your interns as if the parents or the baby isn’t there. Talk to them as well. Don’t just be so abrupt and cold and rude and, you know. I think that that could go for the majority of the medical profession as a whole, not just doctors, but nurses and everybody else. (Anne)

While the participants considered physicians responsible for fully disclosing information, they also acknowledged that physicians are not, as Madeline quipped, “God Junior.” The participants recognized that physicians cannot be expected to be completely all-knowing:

I think we sort of put physicians on a pedestal although they many times ask for it. . . . Doctors aren’t perfect, but I think we also expect a lot from them and they’re not miracle workers. They’re just people. (pause) They’re just people. (Madeline)





Consequently, the participants acknowledged that parents also need to take responsibility for making informed decisions regarding the medical treatment of newborns with disabilities.

Parents' responsibility. Many participants believed that parents should take an active role in acquiring information prior to making treatment decisions for their baby, rather than be passive recipients of information given to them by physicians:

They [parents] should find out as much as they can before they make a decision. (George)

To begin with, the participants made the observation that parents should take into consideration the qualifications of health care professionals who make specific recommendations concerning the medical treatment of their baby:

Do they have the true knowledge to make that statement? . . . Do they understand the baby's disability or are they just making a private statement, "Oh, well, it's just better to let disabled children just go." Or are they speaking from a true understanding from being within that specialized field and knowing, "Okay, some babies born with this disability can make it, but this baby[']s disability] is too severe and therefore, for the interest and the health of the child, . . . just let them go." (Anne)

Alice, in particular, thought that parents of newborns with disabilities should independently research information because of the possibility that physicians may not be forthcoming with information, or may not be informed:

Get all the information on that disability and don't stop until you've found out all the information that you want 'cause some doctors don't tell or don't even know themselves.

Subsequently, parents who rely solely on physicians to provide information may be making treatment decisions based on biased or limited disclosure of information.

The participants also indicated that sufficient time is necessary for **parents** to make informed treatment decisions for their baby:



Don't make a decision right away. Like, think about it a bit and get informed. . . . 'Cause some people may make these decisions without thinking them over a bit and coming down to a place in their head and life where they can make sort of a sound decision. (Peter)

The participants recommended that parents not make treatment decisions immediately, but take time to process the information and to thoughtfully consider their choices:

You can't make those decisions right at the delivery table. (Peter)

I don't know that anybody's able to make a snap decision at that moment because it's usually a shock. (Madeline)

The participants believed that by taking an active part in pursuing information, parents would enhance their understanding and be in a better position to make informed treatment decisions for their newborn.

In brief, the participants perceived the responsibility for making informed decisions regarding the medical treatment of newborns with disabilities as a cooperative effort between both physicians and parents. Moreover, they emphasized that treatment decisions should be informed decisions, based on a thorough disclosure of information and adequate understanding.

This leads to an analysis of the bases upon which treatment decisions are made. Thus, the remaining themes focus on the participants' perspectives regarding criterion factors which may be taken into consideration in making treatment decisions. The first three factors focus on ethical principles; the next three relate to clinical features, and the last two concern external measures.



## Criterion Factors

### *Ethical Principles*

#### Personhood

The concept of personhood, within the context of this study, focuses on society's moral obligation to newborns, based on their status as persons or non-persons. The concept of personhood is subject to a variety of interpretations, with different implications in terms of the ways in which the lives of babies, including those with disabilities, are valued. As such, views concerning personhood may have a further influence on decisions concerning the medical treatment of newborns with disabilities.

When the participants were asked to share their perspectives on the personhood of newborns, all responded unequivocally that they believed that babies are persons. Moreover, the participants believed that the personhood of newborns is not altered if a baby has a disability, regardless of the severity of the disability:

I guess from my own personal perspective, I think babies are people. I think, you know, once they come into this world, they are a person. . . . I mean—disabled, not disabled—once you are in this world, you are a person and you count. (Anne)

Although all the participants affirmed the personhood of newborns, there were differences in the manner in which they related the concept of personhood to the making of treatment decisions. Some participants thought that personhood should not be a factor, as all babies are persons. George, Madeline, and Heidi, who shared this perspective, commented that medical treatment should be administered to babies with disabilities accordingly:



Babies are people, the same as anybody else. I think they deserve a chance as anybody else. (Madeline)

Other participants, however, believed that the personhood of newborns is relevant to making decisions regarding medical treatment. Anne and Charlotte asserted that, because babies are persons, careful consideration needs to be given to the making of treatment decisions, particularly termination of medical treatment:

I feel very strongly that regardless of the degree of disability at birth, that baby is a person. . . . And therefore, care and caution should be given in withholding or withdrawing treatment. I think you are insulting the personhood of that baby—that disabled baby—by treating it as though it's not human because it's defective. (Charlotte)

Another aspect of personhood was raised by George, Peter, and Alice, who thought that the concept may be more of an issue with regard to abortion and the status of the fetus, than with regard to decisions concerning the medical treatment of newborns with disabilities:

I know some people think that before you're born, [you aren't a person]. That's like with the whole abortion issue. (Peter)

Additionally, Peter perceived that some may ascribe to beliefs that newborns—especially those with disabilities—are not persons, in order to abdicate responsibility for the care of babies with disabilities:

No, I think it's just an easy way out. You see, a lot of people I think, not a lot, but probably some people, this is like, "I'm not able to look after this person," you know. They don't want the responsibility of it.

In short, in discussing the personhood of newborns, the participants did not focus on babies' status as persons or non-persons. All of them believed that babies are persons and should be treated accordingly.





## Sanctity of Life

The sanctity-of-life ethic states that human life is of inestimable value and significance in all its dimensions. It considers every human life of equal inherent moral worth and values human life independent of its qualities or capacities. The principle of the sanctity of life makes the preservation and protection of human life its first priority. Consequently, beliefs that are held concerning the sanctity of life also affect decisions concerning the medical treatment of newborns with disabilities.

Only one participant, Peter, put forward the sanctity-of-life ethic as a consideration in making treatment decisions of babies with disabilities. He repeatedly indicated that he believed that “everybody has a right to life.” Accordingly, Peter affirmed that all newborns with disabilities should receive medical treatment:

To me, everybody's a human being. . . . Just because they have something that's not normal or they will need a lot more support in life, it's not to say, “Let's kill them because they aren't like you and me.” Yeah, oh, no, I don't believe in killing. . . . Just because they have a disability, and that can be even a severe disability, I think that we don't have the right to let somebody live or die because of that.

The sanctity-of-life ethic is often contrasted with the principle of the quality of life. Notwithstanding, while Peter regarded all babies as possessing an inherent human right to life, other participants raised quality-of-life considerations in making treatment decisions of newborns with disabilities.

## Quality of Life

Many babies who survive with medical treatment have significant disabilities for their entire lives. As such, quality of life may be taken into consideration when making decisions regarding the medical treatment of newborns with disabilities.



Several participants shared similar views concerning the relevance of quality-of-life judgments in making treatment decisions.

The participants who regarded quality of life as a factor to be considered indicated that decisions to withhold or withdraw medical treatment from babies with disabilities is acceptable when a diminished quality of life is expected:

I feel if there's not gonna be a good quality of life for that person, I feel that it would be all right to withhold life-sustaining treatment for that person. (Anne)

However, a significant challenge in applying a quality-of-life criterion to treatment decisions is defining "quality of life." As Anne observed, "Quality of life, I know is a very iffy kind of term. I mean, everybody defines it differently."

The participants proposed several perspectives in assessing quality-of-life considerations. For instance, Charlotte identified quality of life with the medical condition of newborns with disabilities. She stated that, in circumstances where a baby is born with a severe congenital malformation such as anencephaly, the very limited quality of continuing life should be considered when making decisions to withhold or withdraw medical treatment:

If it's a situation where the baby is born without a brain, yes, that's where the quality of life comes into consideration. . . . And I believe I could, with a degree of comfort say, "Treatment must be humanely withheld because there's no quality of life for that baby."

Similarly, Anne considered the withholding or withdrawal of medical treatment acceptable in cases in which quality of life would be diminished by pain and suffering:

If you're gonna be in a great deal of pain and there's gonna be no way to manage that pain, then, I feel, why make that person suffer?



Another position, proposed by Anne and Alice, associated quality of life with independence. They stated that if a baby will not have the opportunity to attain independence, and will have to live in a residential facility or another segregated setting, then, on the basis of quality-of-life judgments, a decision may be made to withhold or withdraw medical treatment:

The definition of quality of life is not being stuck in a nursing home or a hospital for the rest of my life and having a little bit of dignity. . . . I have sympathy for people laying in beds and left there. What kind of dignity is that? Yeah, no respect. (Alice)

Quality of life would be being independent or achieving as much independence as you can. . . . I don't think living in an institutional environment or being segregated from what society has to offer, what life is there then? What can you get from it? What can you achieve from it because you're just in such an isolated shell? You're missing out on so much. What could you see? What could you live? So then, if it came down to that, I would consider it [withholding or withdrawing medical treatment], you know, because what kind of life is it to live in a little, tiny shell? (Anne)

Thus, although the participants viewed quality of life from different positions, it was considered an important criterion in making treatment decisions. Regardless of the manner in which the participants defined quality of life, they indicated that decisions should be made to withhold or withdraw medical treatment from babies with disabilities when their quality of life is expected to be extremely diminished.

### *Clinical Features*

#### Type of Disability

The participants were asked whether or not the type of disability would influence their decisions concerning the medical treatment of newborns. Specifically, they were asked to share their perspectives about babies with mental and/or physical disabilities.





With the exception of Madeline, who asserted that “a disability is a disability,” the participants noted that they considered mental and physical disabilities differently. This distinction is portrayed in the following childhood memory recounted by Charlotte:

When I was in my early teens, I used to go to a junior high school out in the country. I rode on a bus that took mentally retarded kids to a nearby special school and I can remember that I was never ever happy on that bus. I felt terribly uncomfortable around mentally retarded people and yet, I felt very guilty about it. I really struggled inside myself. I felt that there was a part of me that was wrong in thinking this because who was I to be judgmental? I'm physically disabled. And it took me quite a few years to work it out. . . . I now feel that [people with mental disabilities] can teach us a lot.

The participants also indicated that they made a distinction through their dissatisfaction at being perceived by others as having a mental disability on account of having a physical disability:

We still have to fight for many things and in terms of within society, with respect to getting respect from other people, you know, being thought of as a person rather than, you know, some people still view, “Well, if you've got a physical disability, you've got a mental disability.” So then, there's that gap that you still have to work on. (Anne)

I was very astounded when people treated me as being less than, and it took a long time, but I finally connected that to the fact that I was physically disabled. Because they could see the physical disability, they connected that to what they thought to be a mental disability, too. (Charlotte)

Although most of the participants indicated that they differentiated between mental and physical disabilities, several stated that the type of disability would not affect their decisions concerning the medical treatment of newborns. Anne, Charlotte, Peter, and Madeline held that the type of disability is irrelevant in making treatment decisions:

I don't see any difference in the treatment recipient receiving treatment for a baby whether they be mentally or physically disabled. (Anne)



Whether it's mental, physical, . . . I don't care what the disability is. I think other factors are much more relevant and important than the type of disability. (Madeline)

In contrast, George stated that the type of disability should be a consideration in making treatment decisions. George commented that he would be more inclined to advocate medical treatment for babies with physical disabilities than for those with mental disabilities:

If the child was just physically disabled, I would be more willing to keep the baby alive versus if it was mentally disabled, or doesn't have much potential in the baby developing as his own person, like kind of being stuck at a six-year-old level. It kind of wouldn't be really (pause) I don't think it would be fair to the child. . . . I've been around where there was this person who did have a severe mental disability. . . . He couldn't communicate what he wanted so he'd be constantly screaming all the time. So then, I was like, "Ugh!" I wouldn't want a child to have to go through something like that. Yeah, it would be "pull the plug" kind of thing with the mental disability, but if it's just a physical disability, then you would keep it.

Similarly, Heidi deemed that her decisions concerning the medical treatment of babies would depend on the extent of the mental disability. Heidi believed that medical treatment should be withheld or withdrawn in circumstances where babies are diagnosed with more severe forms of mental retardation, due to their vulnerability to abuse, exploitation, and neglect:

It depends on how mentally handicapped is progressed. Like, if it's really progressed, (pause) they shouldn't, (pause) this sounds awful, but I feel sorry for them because they don't know what's going on. They are put in group homes where people can go and punch them or mistreat them and stuff like that. They can't say anything, right? So why should we put them through that? . . . And their moms and dads are not there to visit them and they don't care for them. . . . The kids who are in wheelchairs and just sit and are being driven around in wheelchairs, I think they should not have that chance.

Alice remained undecided and refrained from clearly stating her views with respect to treatment decisions based on the type of a baby's disability, particularly



babies with mental disabilities. Alice had mixed feelings concerning the issue in light of her own personal encounters with persons with Down syndrome:

That's a tough question. I've been around people who have Down syndrome and some of them are just the neatest people I've ever seen and then some of them (pause) not. So, it's a tough choice.

The participants, notably those for whom the type of disability was a factor, seemed more likely to support the medical treatment of babies with physical disabilities rather than treatment of those with mental disabilities. At the same time, the extent of the disability seemed to be of importance in the treatment decisions.

### Extent of Disability

Significant technological developments in neonatology have resulted in the prolongation of life and improvement of health for many critically-ill newborns. On the other hand, however, the projected future of babies requiring medical treatment is often characterized by considerable uncertainty regarding the degree and range of disability. Hence, the participants were asked to share their perspectives concerning the medical treatment of newborns, regardless of the severity of the disability. Unlike the diverse responses put forward with respect to the influence of the type of disability in making treatment decisions, most of the participants concurred that the extent of the disability would be a determining factor.

Madeline, alone, emphasized that the extent of disability is irrelevant in making treatment decisions:

It doesn't matter the level of disability. It doesn't matter. Like, that is just a minor factor 'cause I think a disability is a disability. Yes, the more severe, the more care. But . . . you learn how to cope with all levels of that.





At another point during the interview, Madeline reasserted that she had “seen children who are profoundly and severely disabled that have very good lives and [that] they can.”

The remaining participants, however, stated that the severity of a baby's disability would be a consideration in making treatment decisions:

Would depend on the level of disability. (Anne)

Number one, as far as criteria goes, the first one would be the medical consideration—the actual state of the baby, the degree and severity of disability. (Charlotte)

Well, for me, I would say it depends more on the severity of the disability. (George)

Generally, the participants believed that medical treatment should be withheld or withdrawn in conditions in which a baby is chronically and irreversibly comatose:

The only time I would be definitely for withholding, would be if it could be proven to me medically, beyond a doubt, that that child was so congenitally disabled that there was little or no hope. Whether it was a lack of a brain or some other really crucial functioning ability. (Charlotte)

I've seen some cases in which there were babies born with just a brain stem—it's kinda pointless. (George)

If somebody is basically a vegetable and you know, hooked up to a machine and that's the only way they're gonna be able to survive for the rest of their life, well then, I think it's more humane to let them go. . . . If all the experts said there was no way that this person will ever be able to function at all. Like, if they were basically being kept alive by a respirator and all the other medical—like, I know they can keep anybody alive as long as they want—then I'd say, “Let's just let them go.” (Peter)

At the same time, George stated that medical treatment should be pursued if a baby had “reasonable potential for surviving to maybe a decent age and actually being able to have somewhat of a normal life.” Peter emphasized that the diagnosis of a disability in itself does not justify the withholding or withdrawal of treatment:





Just because somebody has an impairment or a disability, or is not quote “normal,” then I, of course, believe that a humane society should give them those opportunities to continue to live.

Peter also commented on the challenges inherent in making treatment decisions on the basis of the extent of disability. More specifically, he remarked on the complexity and ambiguity in determining the point at which medical treatment should be withheld or withdrawn:

Just how disabled is this person? Are they just gonna basically be a vegetable? See, that's where the gray area is. There's a difference between something that's never going to get any better than it is—like, it's just basically living off a machine—to somebody who is born without an arm or a finger or whatever. See, it can get to the point where just because somebody's got something that's not normal when they're born, should we just not let them live?

On the whole, the participants shared similar views relating to the significance of the extent of disability in making treatment decisions of newborns. With the exception of Madeline, the participants deemed that the extent of disability should determine whether or not medical treatment is withheld or withdrawn.

### Prognosis

Related to the extent of disability is the ultimate prognosis of newborns with disabilities. While it is often possible to diagnose accurately and precisely newborns' disabilities, prognosis is considerably more challenging. Some babies may have complex anomalies that make it virtually impossible to predict, with any certainty, the probable outcome of the diagnosed medical condition. Most of the participants commented on this matter, including Charlotte, whose following quote depicts the complexity of the issue:

If it has been proven beyond a benefit of a doubt that that child is severely, congenitally compromised, then they [the physician and the parents] should be



allowed to make a decision to have life-sustaining medical treatment discontinued. For example, if you take a baby that is born without a brain, what is the purpose of letting that child live? *However, on the flip side, is medical science so perfect that you can decide that this disabled child should live and that one should die?* [italics added] If it's something like where there is no brain and it can be medically proven, yes. But what if it's a different situation?

Of the seven participants, only George related specifically the determination of the medical treatment of newborns with disabilities to their prognoses. George stated that medical treatment should be withheld or withdrawn if a baby would grow to be "lower functioning than [me]." George also declared that if the likelihood that a newborn would die within six months was more than 70%, then one should "look at instead of letting this baby suffer, to pull the plug." However, if the probability of death was reduced to 20%, George thought that one should "take it as far as you can."

Although the other participants refrained from explicitly relating medical treatment decisions of newborns to their disabilities and prognoses, they alluded to the risks inherent in making treatment decisions in terms of newborns' prognoses. These participants considered the prediction of the long-term outcome and potential of babies with disabilities to be difficult and largely uncertain:

Like I say, how can you judge? I mean, how is there a way to know how far your child can develop? I mean, you can have what you perceive to be a normal baby and yet, in the future, they could have many problems. (Anne)

One never knows what a human being is capable of. Nobody knew what I was capable of and look at what I've done. . . . Remember that no matter what the child's disability, you have potential there. It may not be what you've defined as potential, but it's there. (Charlotte)

Nobody can determine an individual's ability when they're born. . . . You never know what the potential of somebody is until they've had the opportunity. Like, you can't say, "They will," or "They will not do this, that, or the other." (Madeline)



At birth, they [physicians] don't know exactly what it's going to be like at all.  
(Heidi)

Therefore, while the participants alluded to the relation between the prognoses of newborns with disabilities and the making of treatment decisions, most of the participants seemed unwilling to advocate making these decisions solely on the basis of the prognoses.

### *External Measures*

#### Financial Considerations

The medical treatment of newborns with disabilities is a particularly expensive form of medicine. The extraordinary cost of neonatal intensive care gives rise to the question of whether financial considerations should influence decisions concerning the medical treatment of newborns with disabilities. All the participants addressed this issue, giving a range of responses.

All stated that the cost of medical treatment should not be a consideration in making treatment decisions of babies with disabilities:

I don't think that [cost] should be a factor. . . .I don't think you can base whether or not to let them live, based on that. (Madeline)

A few participants held this view more strongly than others, claiming that finances have absolutely no relevance in treatment decisions. In particular, when Peter was asked what extent, if any, cost should influence treatment decisions, he responded emphatically, "None. None at all," and indicated that there was no need to elaborate on his response. Similarly, Heidi maintained that medical treatment should be administered to newborns with disabilities regardless of the cost:

I think babies should receive treatment whatever the cost. . . . Who cares about the cost? . . . They should say, "Erase the cost." The baby comes first. (Heidi)





However, other participants were not as definitive in asserting the irrelevance of cost in making treatment decisions. These participants echoed Charlotte's remark that "money should be the least of the concerns, but unfortunately it has to be. . . . It's the reality. Money is the reality." Charlotte, George, and Alice alluded to the allocation of resources and indicated that the cost of medical treatment must be taken into account in making treatment decisions depending on a baby's expected prognosis and anticipated quality of life:

I think that cost should come into it based upon the baby's medical situation. . . . What is the point of maintaining a child when there may not be a quality of life, because the financial burden to the family, the province, the state, whatever, is phenomenal. And that has to be taken into consideration. Money that is spent on maintaining a baby without a brain when that money could be used to help someone who really needs it—who could really be helped.  
(Charlotte)

In fact, at one point during the interview, Alice stated specifically that the financial cost to families would be a primary consideration in making decisions to withhold or withdraw medical treatment from newborns with a poor prognosis:

If it's gonna be a long costly battle and if the parents can't afford and the government won't help, . . . I would withhold [treatment] if it's gonna cost more than what the family can afford or more than what the government is gonna allow and there's no chance of the child being functional. . . . I'd want to know in advance how far the health care system is going to go to help this family and this child out.

At the same time, the participants observed that while finances should not be a factor in making treatment decisions at birth, it often becomes an issue in the long-term care of newborns with disabilities:

[Cost] is a factor that I think will come up in the later years. (Madeline)



Anne and Charlotte referred to the expenditures parents may incur in raising their baby, as many newborns with disabilities are at risk for developing long-term medical conditions which require nursing care assistance and other medical equipment and supplies:

A parent would have to look at cost for the future. Because let's say the child needs so much medication and like, a wheelchair and other aids in order to get around, and you'll need to adapt your home. So cost does become a factor later on. (Anne)

Likewise, George expressed concern for the long-term care and welfare of newborns with disabilities in circumstances where parents lack the financial resources to provide adequate care for their baby:

If the family doesn't have much money and relies on social programs for pretty much most of their funding and what not, then that will have to be a consideration. 'Cause this kid may have a good chance of surviving, but its chances will be quite poor if it can't get the proper care. It may end up suffering and spending more time in the hospital 'cause it's subjected to poor care at home. (George)

Equally important, George, Madeline, Peter, and Alice addressed the financial consideration of individuals with disabilities as they make the transition to adulthood and consider living independently in the community:

I don't think that [cost] should be a factor, but I also know that living on an AISH [Assured Income for the Severely Handicapped] is a very difficult lifestyle choice. . . . I know of a single fellow who has 24-hour aides. Now, the cost for that fellow to live in the community, to get that kind of support versus a group home where you have one staff for three or four people—society can't afford that. It's an ideal and it's wonderful, but realistically, a one-on-one support system—that's three to four thousand dollars a month. (Madeline)

Another monetary aspect which the participants mentioned related to who should take responsibility for the expenses that are incurred in providing both immediate and long-term medical treatment of newborns with disabilities. The



participants who remarked on this matter indicated that the cost of medical treatment should not necessarily be the responsibility of parents and that the government should provide the needed funds:

If the family can't afford treatment, there should be social programs out there where they could get the funding for treatment. (George)

Moreover, Anne and Alice reasoned that parents face many other challenges in caring for children with disabilities and that the cost of medical treatment should not be an additional concern:

Parents are expected to pay for costs that, you know, they shouldn't have to face. Because it's draining enough to raise a disabled child without thinking of the emotional drain of the fact of money. (Anne)

It shouldn't be a cost to the parents. It should be covered 'cause they've gone through a lot of stress already and, you know, why put them through more stress than they ought to. (Alice)

In discussing the cost of the medical treatment of newborns with disabilities, the participants addressed the question of finances not only as it relates to treatment decisions at birth, but also with regard to the long-term care of children with disabilities. While the participants stated that finances should not influence treatment decisions, they also indicated that the cost of medical treatment is a multifaceted issue which does not easily lend itself to simple, categorical responses.

### Social Support

Another factor related to the long-term care of newborns with disabilities is the extent of social support for and from families in coping and caring for babies with disabilities. Throughout the interviews, all the participants mentioned the significance of social support, not only with regard to its instrumentality in influencing the prognoses of the babies, but also in relation to making treatment





decisions. Although the participants indicated that the extent of social support is not necessarily a determining criterion in making treatment decisions, they expressed that it should be taken into consideration:

I don't know if [social support] is an easy way to make a judgment to turn the life-support system off or on. I don't think it is. . . . I've seen children that are profoundly and severely disabled that have very good lives and they can. *But* [emphasis added] you have to have some kind of a system that's willing and able to support that. (Madeline)

Support For Families. The participants believed that discussions between parents and health care professionals in which the availability of various resources and services is assessed are an integral component of making treatment decisions. They addressed the need to ensure the integration of support for families in coping and caring for babies with disabilities:

I would discuss as many options as possible with the parents . . . about what can be done for that child once they're released into the parents' care. What resources are out there in the community? What backup support are the parents and their families going to have? (Charlotte)

What's the support system? When this child goes home from the hospital, who do you have to assist you? Who's in your life? What do you see that you need? Are you going to take this child home with you? (Madeline)

Charlotte suggested several forms of support which she believed should be available to help families cope effectively with a newborn's disability and to provide adequate care for that baby:

This support would be therapeutic, both physical and psychological; it would be educational; it would be community based that has daycare, release care; support such as camps for special needs children, so on and so forth.

The participants' assertion of the indispensability of support for families seems to result from an understanding of the emotional impact of disabilities on families, and the need for families to be able to adapt to the changes and challenges of





having a baby with a disability. Anne observed that caring for a baby with a disability affects all family members; a supportive relationship is important not only between parents, but also among extended family members:

You have to talk to your spouse because you're in it together. It's not a one-way street. It's the two of you together that raise a child and then, you know, I mean, yes, there's single parent families, there's separated families, there's so many forms of families, but a family as a whole, raises a person. And so, you talk to family and say, "Okay, if I need help here, can you back me up? I may need emotional support from you, from you, from you. Can you help me?"

Similarly, Charlotte remarked on the effect on siblings of a baby with a disability. She believed that support for families is critical to help parents balance their parenting efforts such that siblings are not adversely affected by the extra care and time that may be required by the baby:

When you have to spend all your energy on your developmentally delayed, physically disabled child, you don't have a lot of energy to care for the siblings and that causes a lot of negative family dynamics. Even the able-bodied siblings end up being parents, in a sense, to each other and to the disabled child.

Moreover, the participants' emphasis on the need for parents to be aware of the different social support systems, and ensuring that the resources and services are in place, reflect their concern for the adequate care of newborns with disabilities. Madeline voiced concern regarding circumstances in which parents lack the strategies and resources to help them cope with their baby's disability, and the possible negative consequences of child abuse or neglect:

Maybe it's a single mother who has enough problems coping with just existence and her own survival. And if she has a multiply disabled child that needs even more attention, is that child going to get the attention, or is he or she going to be even more traumatized or potentially abused?



Equally important, the participants acknowledged that, despite the availability of various resources and support for families, there may be parents who are unable or unwilling to provide adequate care for their baby. In such conditions, the participants stated that alternative provisions for the baby's care need to be considered:

If the parents aren't willing or don't think they're able to provide long-term treatment for the child, they need to be looking at options as far as what would be best for the child. (George)

However, at the same time, the participants were divided as to what they considered the best support system for newborns with disabilities in situations in which a baby's immediate family is unable or unwilling to care for the infant. Peter advocated the involvement of social services and the placement of the baby in foster care, objecting to the inability of parents to cope with their baby's disability as a basis for withholding or withdrawing medical treatment:

I can understand . . . that not everybody's cut out for that sort of parenting or responsibility. But rather than shaking the kid to death, or gassing them, or whatever, let somebody who can look after them, you know. . . . [Parents] should turn [the baby] over to the state or the government and then social services would, you know. It's just not, "Oh, no, we can't do it. Let's just put it in the dumpster," you know what I mean? . . . I don't think putting it under is the answer in a scenario like that. If you can't, somebody else can. I mean, there's foster parents that are under the whole social system that we have. We live in a country that provides that.

George, on the other hand, thought differently: "Yeah, that's pretty bad when it happens to a normal child. Never mind one that has special needs." Anne, Madeline, and Alice also took exception to the placement of babies with disabilities in foster care or residential institutions:

I mean, if you're in an institution, you're a number. You're not a person. And so if you're in pain and you're crying, "Well, okay, we'll get to you when we can." That's the way it is nowadays, unfortunately. (Anne)



If [parents] choose to continue to try to allow the baby to live, but are not prepared to parent that child, I'm not sure that putting this child with probable disabilities into a foster system is beneficial. . . . I see so many kids in the foster system and . . . I think it's improved somewhat over the years, but it's still not a good system. . . . The children who are shuffled into a foster system . . . come out really (pause), I guess overwhelmed is a good word. They really don't have a good base to start from. (Madeline)

Support From Families. Although the participants were divided concerning social support systems for newborns with disabilities, all concurred that support from one's family is optimum. This view is attributable to their personal experiences. Charlotte and Peter recounted the value of the support they received from their families in fostering their ability to cope with their disabilities:

In many ways, my experience of having a disability has been positive. . . . My mother took care of me very well. My older brothers and sisters looked after me, too. So, I was constantly surrounded by loving people. (Charlotte)

I had support from my family—a lot of support—and I still do. And I think you have to have that. Well you don't have to, but, I mean, it makes it a lot easier. . . . If you don't have a good, solid family background or support, it's gonna be a lot more difficult. (Peter)

Likewise, Heidi credited the support she received from her mother with the level of success she has attained in living independently and being integrated into the community:

My mom wanted so much for me to exceed the limit and I did exceed the limit. And I thank her for doing that because I wouldn't be here today. I'd probably be in a group home—not with the kids, not with my husband—just waiting to die.

Notwithstanding the various aspects raised by the participants, Charlotte pointed out the difficulty of making treatment decisions, because of the inability to determine beforehand the availability of necessary resources and services:

A lot . . . depends upon what resources are going to be out there for them. And that can be very difficult. Some of it you can see immediately, others





you have to work towards. And who's to say how that will work out? So some of it is pretty long term and unforeseeable.

Perhaps Anne summed it up best when she advised parents, "You need to be able to know in your mind that that's what you're going to do and know when and where to get help when times go rough, and they will."



This chapter examined the perspective of seven individuals with disabilities concerning decisions regarding the medical treatment of newborns with disabilities. The findings indicate that the issue is not only difficult and complex, but also multifaceted. Various factors were found to affect the making of treatment decisions. Moreover, the diversity of the participants' responses reveals that they do not hold a single, homogeneous perspective. The findings of this study, focusing on its meaning and implications, will be discussed in the remaining chapters.



## CHAPTER SIX

### SYNTHESIS OF THE PERSPECTIVES

The purpose of this study has been to examine the perspectives of people with disabilities concerning decisions regarding the medical treatment of newborns with disabilities. Although many, including health care professionals, ethicists, legal practitioners, and parents have articulated their views on this issue, few, if any, studies have examined treatment decisions of newborns from the standpoint of people with disabilities. Researching the issue of treatment decisions specifically from the perspective of people with disabilities has implicitly contrasted their views with the perceptions of others, leading to the expectation that their views would be distinct. However, the results of this study, as presented in the previous chapter, reveal that the participants do not hold a separate, uniform perspective. On the contrary, the participants' perspectives concerning treatment decisions are both diverse and complex. These findings parallel the observations of Shapiro (1993) in his investigation of the disability rights movement in the United States. He describes the movement as a mosaic, "made up of people with complex and varying opinions" in which "diversity is its central characteristic" (p. 11). While no claim can be made that the participants of this study are representative of all or even most people with disabilities, the heterogeneous responses indicate that the perspectives of people born with disabilities concerning treatment decisions are generally comparable to the views reflected in other research studies conducted with mostly able-bodied members of society. This chapter will reexamine the themes presented in the preceding chapter,



addressing the participants' perspectives in light of the views discussed in the existing literature.

## **Best Interests**

### Best Interests

The findings of this study indicate that although all the participants generally preferred the administration and maintenance of medical treatment, several also recognized that there may be circumstances in which decisions to withhold or withdraw medical treatment are in the newborn's best interests. The challenges inherent in ascertaining and maintaining the best interests of the newborn were revealed in the participants' responses as they observed that one person may perceive a baby's best interests differently from the way in which they are perceived by others. As a result, there may be a conflict between the interests of the parents or society and of the newborn.

Both the Canadian Pediatric Society (2000) and the American Academy of Pediatrics (1995) advocate the making of treatment decisions in the best interests of the newborn:

The primary concern of physicians caring for children must be the best interests of the individual child. All infants and children have intrinsic value and deserve our respect and protection. This is true whether or not they are handicapped or have the potential to be handicapped and regardless of whether this handicap is physical or mental. (Canadian Pediatric Society, 2000, p. 1).

However, despite the publication of such position statements, which also outline guidelines for determining the best interests of newborns with disabilities, other literature reveals that there is considerable variation in the interpretation of the "best interests" standard.



On the one hand, there are those who argue that the best interests of newborns cannot be determined in isolation from the values and concerns of others, proposing that the interests of the newborn be balanced with those of the parents and society (Dellinger & Kuszler, 1995; Silverman, 1992; Weir, 1995). Campbell and McHaffie (1995) deem that a baby's best interests are "inextricably interwoven" with the interests of his or her parents and that part of the health care professionals' "clinical wisdom consists of responsibly weighing interests and creatively resolving *apparently irreconcilable conflicts* [emphasis added]" (p. 341).

In contrast, others emphasize the critical importance of upholding the best interests of the newborn in making treatment decisions, even in circumstances in which the baby's interests conflict with those of the parents or society (Dellinger & Kuszler, 1995; Ellenchild & Spielman, 1996; Weir, 1995). Dunn (as cited in Ellenchild & Spielman) asserts that treatment decisions must be based on the best interests of the baby "regardless of the impact of that decision on family life" (p. 72). Thus, while the assessment of a baby's best interests is not necessarily always an issue, its discernment in making treatment decisions of newborns with disabilities is challenging and complex.

## **Procedural Aspects**

### Surrogate Decision-Makers

The participants in this study generally agreed that decisions concerning the medical treatment of newborns with disabilities should be a group process. While parents, physicians and other health care professionals, ethics committees, and courts were proposed by the participants as decision-makers for newborns with disabilities,





views concerning the degree to which these four classes of surrogate decision-makers should participate in the making of treatment decisions varied. Similarly, there are other studies which reveal considerable differences of opinion concerning who should make these treatment decisions.

Although parents were favored as the primary decision-makers for newborns, most of the participants of this study indicated that treatment decisions should not be left solely to the parents. Likewise, current studies reveal that there is increasing support for parental involvement in the making of treatment decisions (Batshaw, 1997; Ellenchild & Spielman, 1996; Lee, Penner, & Cox, 1991; Saigal et al., 1999; Wall & Partridge, 1997). Although several researchers (Canadian Pediatric Society, 2000; Saigal et al., 1999) regard parents as the most appropriate surrogate decision-makers, others (American Academy of Pediatrics, 1995; Ellenchild & Spielman, 1996; Lee et al., 1991; Silverman, 1992) recommend a team approach involving both parents and health care professionals in treatment decisions.

At the same time, however, research (Ellenchild & Spielman, 1996) indicates that once newborns are referred to the neonatal intensive care unit (NICU), parental participation in the decision-making process is limited, perhaps reflecting the findings of studies which acknowledge parental involvement, but state that the final decision regarding medical treatment should be the physician's responsibility (Campbell & McHaffie, 1995). Other literature also reveals opposition to the role of parents as surrogate decision-makers, often disenfranchising parents in the decision-making process. Reasons including the lack of medical expertise and the emotional impact of the birth of a baby with a disability are generally cited for rendering parents



inadequate decision-makers (Batshaw, 1997; Bopp & Coleson, 1996; Ellenchild & Spielman, 1996).

Similar to the pattern of the responses of the participants in this study, research that examines the issue of who should make treatment decisions for newborns with disabilities focuses primarily on parents and physicians and other health care professionals. However, references have also been made to the involvement of ethics committees and courts. In correspondence with the views held by the participants, the involvement of ethics committees comprised of multidisciplinary teams has been recommended particularly in circumstances in which there is disagreement between parents and health care professionals, as well as in making decisions to abate treatment (American Academy of Pediatrics, 1995; Batshaw, 1997; Beauchamp & Childress, 1994; Canadian Pediatric Society, 2000; Wall & Partridge, 1997). However, the findings of a study conducted by Lee et al. (1991) revealed that while physicians and other health care professionals supported the involvement of ethics committees, parents objected to the participation of both ethics committees and courts in the decision-making process. In comparison, the two participants who addressed the involvement of the judicial system in the decision-making process presented opposing viewpoints. Nevertheless, courts have not only been asked to address the medical treatment of newborns, but have also established precedents for medically treating critically-ill newborns and, in certain cases, have been regarded as the final decision-maker (Beauchamp & Childress, 1994; James, 1989; Weir, 1984).



## Informed Decision-Making

The necessity for treatment decisions to be based on a thorough disclosure of information and adequate understanding was emphasized by the participants in this study. They believed that both physicians and parents share the responsibility for making informed decisions about the medical treatment of newborns with disabilities.

Similarly, most literature which addresses treatment decisions also makes reference to the concept of informed decision-making or consent. Research indicates that while physicians have the obligation to provide complete and accurate information to parents (Batshaw, 1997; Beauchamp & Childress, 1994; Dembo, 1964/1984; Ellenchild & Spielman, 1996; Silverman, 1987), there is evidence (Bopp & Coleson, 1996; Perlman et al., 1991) that suggests they may not always disclose essential information to parents. In addition, studies have revealed that physicians and other health care professionals may be influenced by their own biases concerning a particular newborn and his or her disability. Not only do physicians severely underestimate the long-term life satisfaction and well-being of people with disabilities (Bach & Tilton, 1994; Gerhart, Koziol-McLain, Lowenstein, & Whiteneck, 1994; Saigal, 2000), but they also significantly underestimate critically-ill newborns' actual chances of survival (Clyman, Sniderman, Ballard, & Roth, 1979; Lee et al., 1991).

However, particularly because of the aforementioned shortcomings and biases, the participants of this study strongly believed that parents should take an active role in acquiring the necessary information to make an informed decision. Interestingly, research which focuses on parental perceptions (Ellenchild & Spielman, 1996) generally found that while parents themselves recognized their need for





information, they disclosed an inability to either assimilate or obtain information because of their lack of medical knowledge and the intimidation of the NICU environment. In fact, McLone's study (as cited in Bopp & Coleson, 1996) revealed that only 52% of parents indicated that they felt they had made an informed decision. Nevertheless, some authors (Batshaw, 1997) note that when given sufficient time and support to consider their choices, treatment decisions made by most parents are thoughtful and responsible.

### **Criterion Factors**

#### *Ethical Principles*

##### Personhood

In discussing the personhood of newborns, all the participants in this study held the view that babies are persons and should be treated accordingly. Several studies indicate that different definitions of personhood have been proposed by philosophers and ethicists whose debates have centered on the determination of whether specific individuals, including newborns, are persons (James, 1989; Lyon, 1985; Smith 1997; Weir, 1984, 1995). However, unlike those who view the determination of personhood as critical to treatment decisions, the participants in this study did not focus on babies' status as persons or nonpersons. Similarly, Ellenchild and Spielman (1996) found that while health care professionals understand the concept of personhood differently, parents did not associate ethical principles such as personhood with making treatment decisions for their babies.



## Sanctity of Life

In this study, only one participant raised the sanctity-of-life ethic as a consideration in making treatment decisions of babies with disabilities. Similarly, references to the principle of the sanctity of life in research are less frequent. The former Surgeon General of the United States, Dr. C. Everett Koop, is often named in association with the sanctity-of-life ethic as it relates to treatment decisions. Koop categorically objects to selective non-treatment, believing in “the sanctity of all life, born or unborn” (Koop, 1989; Weir, 1984, p. 81). In contrast, although the majority of health care professionals, who responded to a survey conducted by Lee et al. (1991), regarded belief in the sanctity of life as an important consideration in the medical treatment of newborns, few equated the withholding of medical treatment to an act of killing. In a similar manner, Campbell and McHaffie (1995) noted that both the medical profession and the judicial system in the United Kingdom “pay lip service to the sanctity of life” (p. 342), while permitting considerable discretionary measures to the acting physician in making treatment decisions.

## Quality of Life

Quality-of-life judgements were regarded by the participants in this study as a factor to be considered in the withholding or withdrawal of medical treatment from newborns with disabilities. The participant who addressed quality-of-life considerations indicated that decisions to withhold or withdraw medical treatment from babies with disabilities is acceptable in circumstances in which a severely diminished quality of life is expected. At the same time, the participants acknowledged the challenges in proposing quality of life as a criterion in making



treatment decisions, as there is no objective measure by which it may be assessed.

Similarly, discussions pertaining to quality of life are prevalent in literature, revealing a broad spectrum of definitions and positions concerning its application as a criterion in making treatment decisions (Beauchamp & Childress, 1994; James, 1989; Walter, 1995; Weir, 1984).

In practice, although the American Medical Association (2000) sanctions quality-of-life as *one* factor to be considered in making treatment decisions, studies indicate that the extent to which the anticipated quality of life influences the making of treatment decisions for critically-ill newborns varies considerably (Campbell & McHaffie, 1995; Ryan, Byrne, Kuhn, & Tyebkhan, 1993). While there are those who object to making treatment decisions based on quality-of-life judgements because they are subjective assessments (Coleman, 2000; Council of Canadians with Disabilities, n.d.; Koop, 1989; National Council on Disability, 1998; Smith, 2000), Wall & Partridge (1997) have found cases in which quality of life has been the only cited reason for the withholding or withdrawal of medical treatment from newborns.

### *Clinical Features*

#### Type of Disability

The majority of the participants in this study indicated that although they differentiated between mental and physical disabilities, the type of disability would not affect their decisions concerning the medical treatment of newborns with disabilities. At the same time, however, two participants stated that the type of disability should be a consideration in making treatment decisions, specifying that they would be more inclined to advocate medical treatment for babies with physical



disabilities than for those with mental disabilities. Similar to the perspectives of the two participants, Weir (1984, 1995) has indicated that among most health care professionals, ethicists, and legal practitioners, there is consensus concerning the withholding of medical treatment from newborns with certain medical conditions. However, in contrast to this study, the medical conditions identified by these individuals encompass an extensive range of disabilities which cannot be simply classified into the two broad categories of mental and physical disabilities. As such, there is considerable disagreement among these individuals concerning which disabilities give reason for the withholding of medical treatment.

Likewise, with regard to mental disabilities, the literature indicates that varying definitions and standards are used to assess an infant's expected level of cognitive functioning (Endicott, 1990). Furthermore, the views held by health care professionals, in particular, concerning mental disability as a criterion in treatment decisions, have altered over time. Research reveals that, in the past, physicians were more inclined to deny medical treatment to newborns with mental disabilities than to those with physical disabilities (Crane, 1975). Although studies indicate that pessimistic attitudes towards mental disability are still evident among health care professionals (Rutler & Seyman, 1999), it is more difficult to identify current cases in which babies have been withheld medical treatment based on the diagnosis of mental disability.

### Extent of Disability

The finding of this study revealed that, with the exception of one participant, the extent of disability was regarded as a factor in determining whether medical





treatment should be withheld or withdrawn. In contrast to the perspectives of the participants, research conducted by Lee et al. (1991) found that more than 80% of parents believed that physicians should “always try to save all infants even if the infant will most likely be severely handicapped” (p. 111). In the same study, the views held by health care professionals were more varied in that while the majority of nurses considered the severity of a baby’s disability as a determining factor in the administration of medical treatment, physicians were almost evenly divided on the issue. At the same time, most of the health care professionals indicated that in circumstances in which a healthy, very low birth weight newborn subsequently develops a medical condition with a high likelihood of severe disability, the withholding or withdrawal of medical treatment should be given consideration. In a similar manner, although both the Canadian Pediatric Society (2000) and the American Medical Association (2000) do not specify the precise extent of disability at which medical treatment may be withheld or withdrawn, the recommendations outlined indicate that the severity of a baby’s medical condition is a factor to be considered in making treatment decisions. Intolerable and intractable pain and suffering, and extreme neurological damage are stated as acceptable conditions for the withholding or withdrawal of medical treatment from newborns. However, because these conditions are not defined explicitly, such guidelines allow for considerable latitude in making treatment decisions.

### Prognosis

In this study, although one participant related specifically the making of treatment decisions of newborns with disabilities to their prognoses, in general, the



participants seemed unwilling to advocate making treatment decisions on the basis of newborns' prognoses. These participants referred to the risks inherent in making treatment decisions based on the prognoses of newborns, as predicting the long-term outcome and potential of babies with disabilities is difficult and largely uncertain. The findings of the survey conducted by Lee et al. (1991) revealed that, among the health care professionals who indicated that medical treatment should be administered to babies regardless of the extent of disability, uncertainty of the newborn's prognosis was the most frequently reported reason for initiating medical treatment. Similarly, both the Canadian Pediatric Society (2000) and the American Medical Association (2000) specify that in circumstances in which a newborn's prognosis is uncertain, medical treatment should be initiated and administered as necessary. Decisions to withhold or withdraw treatment are recommended to be made once the prognosis is more certain. At the same time, the American Medical Association states that it is not necessary to attain absolute prognostic certainty prior to the abatement of medical treatment.

In practice, the perspectives among physicians concerning the prognosis of a newborn and its effect on treatment decisions vary from country to country (Rhoden, 1986; Ryan et al., 1993; Weir, 1995). Ryan et al. (1993) found that Canadian physicians practiced an "individualized prognostic" strategy in making decisions to withhold or withdraw medical treatment, similar to that exercised by neonatologists in the United Kingdom and Australia. In contrast to the "wait until certainty" or "statistical prognostic" approaches practiced in the United States and Sweden, respectively, the individualized approach allows for selective non-treatment decisions



once a baby's prognosis indicates a high likelihood, but not necessarily near absolute prognostic certainty, of significant disability or death.

### *External Measures*

#### Financial Considerations

In discussing whether financial considerations should influence decisions concerning the medical treatment of newborns with disabilities, the perspectives of the participants in this study varied widely. On the one hand, a few participants stated that the cost of medical treatment should have absolutely no relevance in treatment decisions. However, other participants indicated that the allocation of resources is a reality that must be taken into consideration in making treatment decisions. The range of the participants' responses concerning this matter is similarly reflected in the literature.

Although Ryan et al. (1993) found that none of the treatment decisions documented in their study were made on the basis of the allocation of resources or parental financial constraints, research reveals extensive deliberations concerning the cost effectiveness of neonatal intensive care (Beauchamp & Childress, 1994; Blackman, 1991; Lyon, 1985; Rue, 1985; Smith, 1992). While there are those who believe that financial constraints on health care resources should not be a factor in treatment decisions, many also state that it is unrealistic to disregard the issue of finite resources, indicating that consideration of the allocation of resources is acceptable in making treatment decisions. Interestingly, Lee et al. (1991) found that health care professionals tended to overestimate the costs of neonatal care. Nevertheless, only a





few believed that the limitation of health care resources was sufficient justification to introduce policies restricting the medical treatment of newborns with disabilities.

### Social Support

All the participants in this study emphasized the significance of social support for and from families in coping and caring for babies with disabilities. Although the participants indicated that the extent of social support is not necessarily a determining criterion in making treatment decisions, they expressed that it should be taken into consideration. Studies affirm the necessity of the availability of resources and services to help families cope effectively with a baby's disability and to provide adequate care for that baby (Campbell & McHaffie, 1995; Ellenchild & Spielman, 1996). Equally important, these resources and services are often lacking and unsatisfactory. Nonetheless, the Canadian Pediatric Society (2000) states, "Although the burdens placed on the family must be included in making decisions, neither these burdens nor those placed on caretaking staff or the community can be the primary reason for withholding treatment" (p. 1). At the same time, despite such guidelines, health care professionals who were surveyed in the study conducted by Lee et al. (1991) reported mixed views concerning the influence of social support in making treatment decisions for newborns with disabilities.



In summary, the findings of this study indicate that there is a myriad of perspectives concerning decisions regarding the medical treatment of newborns with disabilities. The diversity and complexity that characterize the perspectives of the participants interviewed in this study are comparable to the broad spectrum of views reflected in the literature. Further, the comparability of the participants' perspectives



to those presented in the literature indicates that the views held by the participants are not necessarily affected by having been born with a disability. Treatment decisions of newborns with disabilities are difficult and complex, as well as multidimensional. As one of the participants, Madeline, expressed during the interview, “[One] can’t give black and white answers for this. . . . It’s not a carte-blanche.”



## CHAPTER SEVEN

### CONCLUSION

Clearly, decisions concerning the medical treatment of newborns with disabilities are challenging and complex. As mentioned previously, although it cannot be stated that the participants of this study are representative of all or even most people with disabilities, the findings reveal that the perspectives of people with disabilities are comparable to the views reflected in the literature. Furthermore, the diversity of the participants' responses indicates that the perspectives of people with disabilities are not necessarily directly affected by having been born with a disability.

At the same time, however, the understanding that the participants' perspectives are independent of their disabilities does not diminish the reality of their disabilities. Throughout the interviews, the participants related their own experiences of disability both positively and negatively. Moreover, the participants emphasized that the limitations that they have experienced are not the result of having a disability, but the repercussion of society's negative attitudes toward disabilities:

I do not feel that my physical disability has stopped me from achieving a lot. I really don't feel that my physical disability has held me back. What has held me back in my experiences as a disabled person is people's attitudes. . . .My experiences of having a disability has been based more on how others have perceived and treated me rather than how I see myself as a disabled person.  
(Charlotte)

Research indicates that societal attitudes toward disabilities tend to overemphasize the negative aspects and undervalue the positive aspects of the lives of individuals with disabilities. Often, the quality of the lives of such individuals is misinterpreted by a fear of disability. In contrast, when the participants were asked to



describe their quality of life, they expressed satisfaction with their lives, indicating that their quality of life is not directly affected by their disability. The following two quotes are representative of the participants' responses:

Quality of life is what you make it, whether you have a physical disability or not. (Anne)

It's not because I'm disabled that I think I have a very good quality of life, but my disability doesn't influence my quality of life that strongly. It's a lot different from a lot of people, I'm sure, and it has its downside, of course, but I still enjoy life. (Peter)

Thus, insights of the disability experience are vital to the understanding of decisions concerning the medical treatment of newborns with disabilities because issues related to treatment decisions are often shaped by society's attitudes toward disabilities. The effect of society's attitude toward disabilities is significant because, in making treatment decisions of newborns with disabilities, there is a predisposition towards "allowing a single trait, the disability, to stand for the whole person" (Ash, as cited in Johnson, 2001). As a result, the implications of this study concern not only those directly involved in the making of treatment decisions, but also society in general.

However, prior to addressing the implications of this study, I would like to conclude with the following remark by Joni Eareckson Tada (2001), the founder and president of Joni and Friends (an organization that ministers to people with disabilities), and an artist, who is paralyzed due to spinal cord injury.

The list of things that I could not do is pretty long—can't peel an orange, can't hold a glass of Coca-Cola, can't hold my husband's hand, can't give him a neck rub, can't whip up an omelet at 2 a.m., . . . . But I *can* hold those brushes and pencils between my teeth, I *can* turn the pages of books using a mouth stick, I *can* get on the telephone to encourage people who are hurting a lot





worse than me, I *can* dictate a letter to lift the spirits of somebody else. There's so many things I *can* do that are so much more important.

This is a message that people in our country need to hear right now what with the "better off dead than disabled" mentality that's pervading society right now, with Kevorkian and assisted suicide. I mean, there is so much fear about disability and we don't need to be fearful. And we certainly don't need to be translating all these fears about disability into what our country thinks is a rational social policy of assisted suicide. No, we need to get out this message that we *can* do—with the help and support of neighbors, friends, family, church—we *can* provide the context in which disabled people can exercise their gifts and their talents. A family does not have to be ripped apart by a handicapping condition. There are resources available. There is help. There is hope. There is nothing to fear.

### **Implications of the Research**

Analyses of the participants' responses and the subsequent reexamination of the participants' perspectives as they relate to the views presented in the literature have led to the following implications of this study.

First, there is a need for increased understanding of the issue of making treatment decisions of newborns with disabilities. While discussions of the numerous aspects related to this issue are at times presented in such a manner that it appears simple and straightforward, the legal, medical, and societal ramifications are diverse and complex. As such, it is important that there be increased cognizance of the numerous perspectives held by those involved, either directly or indirectly, in the making of treatment decisions. Although the marked differences of opinions held by health care professionals, ethicists, legal practitioners, parents, and individuals with disabilities are to be expected, the lack of awareness of the range of views held by all the groups is believed to be a hindrance in attaining a more complete understanding of the issue.



Second, there is a need for increased awareness of the disability experience by the members of society, including both lay and professional persons. Prejudice, stereotypes, and misinformation about people living with a disability increase the likelihood that treatment decisions for newborns with disabilities will be compromised and not made in the best interests of the newborn.

Finally, the need for support for families who are coping and caring for children with disabilities cannot be underestimated. Equally important is the need for support of adults with disabilities. Not only is the provision of information about various resources and services necessary, but it is critical that appropriate support systems be available and in place.

### **Limitations**

Although this study provides insights pertaining to treatment decisions concerning babies born with disabilities from the perspectives of people with disabilities, there are several limitations to be taken into consideration. First, the generalizability of the findings may be limited as a result of the small number of participants and the type of individuals who consented to participate in the study. Also, due to the controversial nature of the research, the participants' responses may reflect social desirability rather than the participants' true attitudes and beliefs concerning the medical treatment of newborns with disabilities. A third limitation of this study is related to the interpretation of the literature and the difficulty presented by the variation in questions and statements used to obtain the views of health care professionals, ethicists, legal practitioners, and parents in comparison to the perspectives of the participants of this study. However, the diversity and complexity



of the participants' perspectives and the comparability to the views presented in literature seem to indicate that these limitations are unlikely to be of significance.

### **Future Research**

Further investigation of this issue from the perspectives of others is needed. Although the views held by members of society concerning the medical treatment of newborns with disabilities do not necessarily correlate with or impact on actual practices or policies regarding treatment decisions, the understanding of others' perspectives is crucial, as individuals' values and beliefs generally underlie their attitudes. Exploration of this issue from the perspectives of other members of society, particularly of individuals who have acquired disabilities as adults, may provide further insights and understanding.

Similarly, examination of treatment decisions from a cross-cultural perspective is recommended for future research. While this study focused primarily on the practice of infanticide in western civilization, cases of infanticide have been documented around the world. In addition, research indicates that the making of treatment decisions varies from country to country. Therefore, a cross-cultural investigation of perspectives on disability and of provision of care for newborns with disabilities may provide a broader understanding of the issue.

Finally, both treatment decisions and the ramification of these decisions on family members are complex and multifaceted. Further research should be conducted with families who have made decisions to administer medical treatment, in order to determine the effects on parents and siblings of living with a child with a significant





disability. As Sir Winston Churchill stated, “It is not the end, it is even not the beginning of the end. It is perhaps the end of the beginning.”



## REFERENCES

American Academy of Pediatrics Committee on Fetus and Newborn, & American College of Obstetricians and Gynecologists Committee on Obstetric Practice. (1995). Perinatal care at the threshold of viability. *Pediatrics*, 96, 974-976.

American Medical Association. (2000). *Code of medical ethics: Current opinions with annotations*. Chicago, IL: Author.

Amundsen, D. W. (1987). Medicine and the birth of defective children: Approaches of the ancient world. In R. C. McMillan, H. T. Engelhardt, Jr., & S. F. Spicker (Eds.), *Euthanasia and the newborn: Conflicts regarding saving lives* (pp. 3-22). Dordrecht, Netherlands: D. Reidel.

Anspach, R. R. (1993). *Deciding who lives: Fateful choices in the intensive-care nursery*. Berkeley, CA: University of California Press.

Bach, J. R., & Tilton, M. C. (1994). Life satisfaction and well-being measures in ventilator assisted individuals with traumatic tetraplegia. *Archives of Physical Medicine and Rehabilitation*, 75, 626-632.

Batshaw, M. L. (Ed.). (1997). *Children with disabilities* (4<sup>th</sup> ed.). Baltimore, MD: Paul H. Brookes.

Bauman, C. (1997). Rethinking the unthinkable: A study of child homicides. *Criminal Reports (Fifth Series)*, 8, 139-154.

Beauchamp, T. L., & Childress, J. F. (1994). *Principles of biomedical ethics* (4<sup>th</sup> ed.). New York: Oxford University Press.

Blackman, J. A. (1991). Neonatal intensive care: Is it worth it? Developmental sequelae of very low birthweight. *Pediatric Clinics of North America*, 38, 1497-1511.

Bogdan, R. C., & Biklen, S. K. (1998). *Qualitative research for education: An introduction to theory and methods* (3<sup>rd</sup> ed.). Boston, MA: Allyn and Bacon.

Bopp, J., Jr., & Coleson, R. E. (1996). A critique of family members as proxy decisionmakers without legal limits. *Issues in Law and Medicine*, 12, 133-165.

Bouillon-Jensen, C. (1995). Infants: II. History of infanticide. In W. T. Reich (Ed.), *Encyclopedia of bioethics* (Rev. ed., Vol. 3, pp. 1200-1206). New York: Simon and Schuster Macmillan.



- Campbell, A. G. M., & McHaffie, H. E. (1995). Prolonging life and allowing death: Infants. *Journal of Medical Ethics*, 21, 339-344.
- Council of Canadians with Disabilities. (n.d.). *Factum of disability coalition intervenors in Latimer case* [On-line]. Available HTTP: <http://www.pcs.mb.ca/~ccd/>
- Canadian Pediatric Society. (2000). *Treatment decisions for infants and children* (Reference No. B86-01). Ottawa, ON, Canada: Author.
- Caplan, A. L. (1992). Hard cases make bad law: The legacy of the Baby Doe controversy. In A. L. Caplan, R. H. Blank, & J. C. Merrick (Eds.), *Compelled compassion: Government intervention in the treatment of critically ill newborns* (pp. 105-122). Clifton, NJ: Humana Press.
- Clyman, R. I., Sniderman, S. H., Ballard, R. A., & Roth, R. S. (1979). What pediatricians say to mothers of sick newborns: An indirect evaluation of the counseling process. *Pediatrics*, 63, 719-723.
- Coleman, D. (2000). Assisted suicide and disability. *Human Rights: Journal of the Section of Individual Rights and Responsibilities*, 27, 6-8.
- Crane, D. (1975). Decisions to treat critically ill patients: A comparison of social versus medical considerations. *Milbank Memorial and Fund Quarterly/Health and Society*, 53, 1-34.
- Dellinger, A. M., & Kuszler, P. C. (1995). Infants: IV. Public policy and legal issues. In W. T. Reich (Ed.), *Encyclopedia of bioethics* (Rev. ed., Vol. 3, pp. 1214-1221). New York: Simon and Schuster Macmillan.
- Dembo, T. (1984). Sensitivity of one person to another. *Rehabilitation Literature*, 45, 90-95. (Original work published 1964)
- Denzin, N. K. (1998). The art and politics of interpretation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (pp. 313-344). Thousand Oaks, CA: Sage.
- Denzin, N. K., & Lincoln, Y. S. (1998). Introduction: Entering the field of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The landscape of qualitative research: Theories and issues* (pp. 1-34). Thousand Oaks, CA: Sage.
- Duff, R. S., & Campbell, A. G. M. (1973). Moral and ethical dilemmas in the special-care nursery. *New England Journal of Medicine*, 289, 890-894.
- Eareckson Tada, J. (Speaker). (2001). *Making friends with the disabled* [Cassette recording]. Colorado Springs, CO: Focus on the Family.



Endicott, O. R. (1990). *The right of persons with intellectual handicaps to receive medical treatment*. Unpublished manuscript.

Ellenchild, J. W., & Spielman, M. L. (1996). Ethics in the neonatal intensive care unit: Parental perceptions at four years postdischarge. *Advances in Nursing Science*, 19, 72-85.

Ferngren, G. B. (1987). The status of defective newborns from late antiquity to the Reformation. In R. C. McMillan, H. T. Engelhardt, Jr., & S. F. Spicker (Eds.), *Euthanasia and the newborn: Conflicts regarding saving lives* (pp. 3-22). Dordrecht, Netherlands: D. Reidel.

Gerhart, K. A., Koziol-McLain, J., Lowenstein, S. R., & Whiteneck, G. G. (1994). Quality of life following spinal cord injury: Knowledge and attitudes of emergency care providers. *Annals of Emergency Medicine*, 23, 807-812.

Girvan, D. P., & Stephens, C. A. (1974). Congenital intrinsic duodenal obstruction: A twenty-year review of its surgical management and consequences. *Journal of Pediatric Surgery*, 9, 833-839.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine de Gruyter.

Gross, R. H., Cox, A., Tatyrek, R., Pollay, M., & Barnes, W. A. (1983). Early management and decision making for the treatment of myelomeningocele. *Pediatrics*, 72, 450-458.

Guillemin, J. H., & Holmstrom, L. L. (1986). *Mixed blessings: Intensive care for newborns*. New York: Oxford University Press.

Health Canada, Laboratory Centre for Disease Control, Canadian Congenital Anomaly Surveillance System. (1997). *Birth defect prevalences in Canada, 1995*. Ottawa, ON, Canada: Health Canada.

Horbar, J. E., & Lucey, J. F. (1995). Evaluation of neonatal intensive care technologies. *The Future of Children* [On-line], 5. Available HTTP: <http://www.futureofchildren.org/>

Horan, D. J., & Balch, B. J. (1985). Infant Doe and Baby Jane Doe: Medical treatment for the handicapped newborn. *Linacre Quarterly*, 52, 45-76.

Horan, D. J., & Delahoyde, M. (Eds.). (1982). *Infanticide and the handicapped newborn*. Provo, UT: Brigham Young University Press.





James, P. L. (1989). *Treatment decisions at the beginning of life: Legal, medical and moral aspects*. Unpublished master's thesis, University of Alberta, Edmonton, AB, Canada.

Jochemsen, H. (1992). Life-prolonging and life-terminating treatment of severely handicapped newborn babies: A discussion of the report of the Royal Dutch Society of Medicine on "Life-terminating actions with incompetent patients, part 1: Severely handicapped newborns". *Issues in Law and Medicine*, 8, 167-181.

Johnson, M. (2001, March). Inside the genetic crystal ball. *New Mobility Magazine* [On-line]. Available HTTP: <http://www.newmobility.com/>

Knafl, K. A., & Howard, M. J. (1984). Interpreting and reporting qualitative research. *Research in Nursing and Health*, 7, 17-24.

Koop, C. E. (1989). Life and death and the handicapped newborn. *Issues in Law and Medicine*, 5, 101-113.

Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage Publications.

Lantos, J. D., & Moseley, K. L. (1995) Infants: I. Medical aspects and issues in the care of infants. In W. T. Reich (Ed.), *Encyclopedia of bioethics* (Rev. ed., Vol. 3, pp. 1195-1199). New York: Simon and Schuster Macmillan.

Lee, S. K., Penner, P. L., & Cox, M. (1991). Comparison of the attitudes of health care professionals and parents toward active treatment of very low birth weight infants. *Pediatrics*, 88, 110-114.

Lyon, J. (1985). *Playing God in the nursery*. New York: W. W. Norton.

Magnet, J. E., & Kluge, E. W. (1985). *Withholding treatment from defective newborn children*. Cowansville, QC, Canada: Brown Legal Publications.

McMillan, R.C., Engelhardt, H. T., Jr., & Spicker, S. F. (Eds.). (1987). *Euthanasia and the newborn: Conflicts regarding saving lives*. Dordrecht, Netherlands: D. Reidel.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications.

Moseley, K. L. (1986). The history of infanticide in western society. *Issues in Law and Medicine*, 1, 345-361.



- National Council on Disability. (1998). Assisted suicide: A disability perspective. *Issues in Law and Medicine*, 14, 273-300.
- Oberman, M. (1996). Mothers who kill: Coming to terms with modern American infanticide. *American Criminal Law Review*, 34, 1-110.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Newbury Park, CA: Sage Publications.
- Perlman, N. B., Freedman, J. L., Abramovitch, R., White, H., Kirpalani, H., & Perlman, M. (1991). Information needs of parents of sick neonates. *Pediatrics*, 88, 512-518.
- Report of the Royal Dutch Society of Medicine on "Life-terminating actions with incompetent patients, part 1: Severely handicapped newborns". (1991). (H. Jochemsen, Trans.). *Issues in Law and Medicine*, 7, 365-367.
- Rhoden, N. K. (1986). Treating Baby Doe: The ethics of uncertainty. *Hastings Center Report*, 16, 34-42.
- Rosenblum, V. G., & Budde, M. L. (1982). Historical and cultural considerations of infanticide. In D. J. Horan & M. Delahoyde (Eds.), *Infanticide and the handicapped newborn* (pp. 1-16). Provo, UT: Brigham Young University Press.
- Rubin, H. J., & Rubin, I. S. (1995). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage Publications.
- Rue, V. M. (1985). Death by design of handicapped newborns: The family's role and response. *Issues in Law and Medicine*, 1, 201-225.
- Ryan, C. A., Byrne, P., Kuhn, S., & Tyebkhan, J. (1993). No resuscitation and withdrawal of therapy in a neonatal and a pediatric intensive care unit in Canada. *Journal of Pediatrics*, 123, 534-538.
- Saigal, S. (2000). Perception of health status and quality of life of extremely low-birth weight survivors: The consumer, the provider, and the child. *Clinics in Perinatology*, 27, 403-419.
- Saigal, S., Stoskopf, B. L., Feeny, D., Furlong, W., Burrows, E., Rosenbaum, P. L., & Hoult, L. (1999). Differences in preferences for neonatal outcomes among health care professionals, parents, and adolescents. *Journal of the American Medical Association*, 281, 1991-1997.



- Shaw, A., Randolph, J. G., & Manard, B. (1977). Ethical issues in pediatric surgery: A nationwide survey of pediatricians and pediatric surgeons. *Pediatrics*, 60, 588-599.
- Shapiro, J. P. (1993). *No pity: People with disabilities forging a new civil rights movement*. New York: Times Books.
- Silverman, D. (1987). *Communication and medical practice: Social relations in the clinic*. London: Sage Publications.
- Silverman, W. (1992). Overtreatment of neonates? A personal retrospective. *Pediatrics*, 90, 971-976.
- Smith, G. P., II. (1992). Murder, she wrote or was it merely selective nontreatment? *Journal of Contemporary Health Law and Policy*, 8, 49-71.
- Smith, W. J. (1997). *Forced exit: The slippery slope from assisted suicide to legalized murder*. New York: Times Books.
- Smith, W. J. (2000). *Culture of death: The assault on medical ethics in America*. San Francisco, CA: Encounter Books.
- Statistics Canada. (1997). *Mortality: Summary list of causes, 1995* (Cat. No. 84-209-XPB). Ottawa, ON, Canada: Author.
- Thurman, S. K. (1993). Intervention in the neonatal intensive care unit. In W. Brown, S. K. Thurman, & L. F. Pearl (Eds.), *Family-centered early intervention with infants and toddlers: Innovative cross-disciplinary approaches* (pp. 173-209). Baltimore, MD: Paul H. Brookes.
- Todres, I. D., Krane, D., Howell, M. C., & Shannon, D. C. (1977). Pediatricians' attitudes affecting decision-making in defective newborns. *Pediatrics*, 60, 197-201.
- van der Heide, A., van der Maas, P. J., van der Wal, G., de Graaff, C. L. M., Kester, J. G. C., Kollée, L. A. A., de Leeuw, R., & Holl, R. A. (1997). Medical end-of-life decisions made for neonates and infants in the Netherlands. *Lancet*, 350, 251-255.
- Wall, S. N., & Partridge, J. C. (1997). Death in the intensive care nursery: Physician practice of withdrawing and withholding life support. *Pediatrics*, 99, 64-70.
- Walter, J. J. (1995). Life, Quality of: I. Quality of life in clinical decisions. In W. T. Reich (Ed.), *Encyclopedia of bioethics* (Rev. ed., Vol. 3, pp. 1352-1358). New York: Simon and Schuster Macmillan.





Weir, R. F. (1984). *Selective treatment of handicapped newborns: Moral dilemmas in neonatal medicine*. New York: Oxford University Press.

Weir, R. F. (1995). Infants: III. Ethical issues. In W. T. Reich (Ed.), *Encyclopedia of bioethics* (Rev. ed., Vol. 3, pp. 1206-1214). New York: Simon and Schuster Macmillan.

Wolraich, M. L. (1980). Pediatric practitioners' knowledge of developmental disabilities. *Journal of Developmental and Behavioral Pediatrics*, 1, 133-136.



APPENDIX A  
INTERVIEW GUIDE

University of Alberta  
Faculty of Graduate Studies and Research  
Department of Educational Psychology

Research Title: Treatment Decisions at Birth: The Perspectives of People with Disabilities  
Researcher: Julia M. Ichikawa  
Supervisor: Dr. R. J. Sobsey



- ☞ What is your opinion about withholding or withdrawing medical treatment from babies who are born with disabilities?
  
- ☞ The projected future of babies requiring medical treatment is often characterized by considerable uncertainty regarding the degree and range of disability. Do you think all babies with disabilities should receive medical treatment regardless of the severity of their disability?
  - **yes:** Is there any instance in which you would agree to withhold or withdraw medical treatment from babies?
  - **no:** In what instances would you agree to withhold or withdraw medical treatment from babies?
  
- ☞ I'd like to read you this quote by Peter Singer who is speaking specifically of babies born with Down syndrome—

We may not want a child to start on life's uncertain voyage if the prospects are clouded. When this can be known at a very early stage in the voyage, we may still have a chance to make a fresh start. This means detaching ourselves from the infant who has been born, cutting ourselves free before the ties that have already begun to bind us to our child have become irresistible. Instead of going forward and putting all our efforts into making the best of the situation, we can still say no, and start again from the beginning.  
[Singer, P. (1995). *Rethinking life and death: The collapse of our traditional ethics* (pp. 213-214). New York: St. Martin's Press]

In other words, according to Singer, an acceptable answer to having a baby born with Down syndrome is to let the baby die.

- Do you agree or disagree with Singer?

- ☞ Do you have the same opinion about babies with mental and physical disabilities?



- ☞ Those who are involved in the decision making process may be influenced by their own personal biases of living with a disability.
  - What is your experience of having a disability?
  - How would you describe your quality of life?
  - In describing your quality of life, is your disability a factor or is it other things?
  - What would you like others to understand about you and your disability?
- ☞ Some people believe that babies do not count as persons. Such people may be likely to withhold or withdraw medical treatment more quickly from babies born with disabilities. What do you think?
- ☞ In some instances, people may think that life is a “fate worse than death” when they see a baby with a significant disability. How would you respond to someone who recommends that it is in the baby’s best interest to withhold medical treatment?
- ☞ Because babies are not able to make treatment decisions themselves, these decisions must be made by others. Who do you think should make these treatment decisions?
- ☞ In your opinion, what criteria should be considered in making these treatment decisions?
  - To what extent, if any, should cost influence decisions about whether babies with disabilities receive medical treatment?
- ☞ If you had the opportunity to advise parents who were in the process of making a treatment decision about their baby, what would you say?
- ☞ What would you say to doctors?
- ☞ If you had a baby born with exactly the same disability that you have and the doctor suggested that medical treatment be withheld or withdrawn, what decision would you make?
- ☞ I would like to end the interview by asking some background information about yourself—
  - Gender
  - Age
  - Level of education
  - Work experience
  - Could you tell me about your disability?
  - Did you receive medical treatment when you were a baby?



- ☞ Is there anything else that you would like for me to know—either about yourself or this issue?
- ☞ Are there any questions you would like to ask me?





APPENDIX B

CONSENT FORM

University of Alberta  
Faculty of Graduate Studies and Research  
Department of Educational Psychology

Research Title: Treatment Decisions at Birth: The Perspectives of People with Disabilities  
Researcher: Julia M. Ichikawa  
Supervisor: Dr. R. J. Sobsey



The purpose of this research study is to examine the perspectives of people with disabilities concerning decisions about the medical treatment of babies who are born with disabilities.

You are being asked to participate in an interview about your perspective concerning this issue. The interview will be approximately one and a half hours. Your responses will be tape-recorded. Your participation is completely voluntary. If you do not wish to participate, then you may say so at any time and the interview will discontinue.

No one but myself will listen to the tape recording. I may use quotes when I write up the results of the research, but in order to ensure confidentiality, your name will not be used.

When I am in the process of analysis, I may check back with you to confirm that my understanding of what you were trying to express is accurate.

Information from this study will be used only for research purposes. I will initially write this research in thesis format. Research findings may be presented and published at a later date. When I have completed my thesis, I will be happy to share the results of my findings with you.

Thank you for your help in this research study.



This is to state that I agree to participate as a volunteer in the above named research study.

I have been made aware of and understand the nature of the research study.



I give my permission to be interviewed knowing that the interview will be tape-recorded. I understand that my participation in the study is confidential. My name will not be used in the analysis, presentation, and publication of the research.

I understand that I may refuse to answer any questions or discontinue with the interview at any time. I also understand that I may decline to participate in or withdraw from the research study at any time.

I have been given the opportunity to ask any questions concerning the research study and all my questions have been answered to my satisfaction.

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Participant

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Researcher

---

Date



## APPENDIX C

### OVERVIEW OF THE PARTICIPANTS' PERSPECTIVES

#### Treatment Decisions at Birth: The Perspectives of People with Disabilities

##### BEST INTERESTS

##### ▶ BEST INTERESTS

##### PROCEDURAL ASPECTS

- ▶ SURROGATE DECISION-MAKERS
- ▶ INFORMED DECISION-MAKING

##### CRITERION FACTORS

- ▶ ETHICAL PRINCIPLES
  - PERSONHOOD
  - SANCTITY OF LIFE
  - QUALITY OF LIFE
- ▶ CLINICAL FEATURES
  - TYPE OF DISABILITY
  - EXTENT OF DISABILITY
  - PROGNOSIS
- ▶ EXTERNAL MEASURES
  - FINANCIAL CONSIDERATIONS
  - SOCIAL SUPPORT

















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